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Children with cerebral palsy and early intervention services

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Abstract

The purpose of this literature and research review is to understand early home intervention services for children with Cerebral Palsy. The review focuses on children between birth and five years old and their families. Studies were reviewed worldwide including the United States, Sweden, Netherlands, and Australia. These studies include information about service providers, different programs for children with Cerebral Palsy and their families, frequency of visits that occur for the children and their families, and the disadvantages and advantages of early intervention services for children with cerebral palsy. The conclusion of this literature and research review also includes recommendations based upon the literature and my personal work in home intervention. The paper concludes with a description of future research needed in the area of early intervention services and children between the ages of birth and five years old diagnosed with cerebral palsy.

Children with Cerebral Palsy and Early Intervention Services

A Graduate Review
Submitted to the
Department of Curriculum and Instruction
Division of Early Childhood Education
In Partial Fulfillment
of the requirements for the Degree
Masters of Arts in Education
University of Northern Iowa

By:
GenaLee Horsfield

This Review by: GenaLee Horsfield

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has been approved as meeting the research requirement for the

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ABSTRACT

The purpose of this literature and research review is to understand early home intervention services for children with Cerebral Palsy. The review focuses on children between birth and five years old and their families. Studies were reviewed worldwide including the United States, Sweden, Netherlands, and Australia. These studies include information about service providers, different programs for children with Cerebral Palsy and their families, frequency of visits that occur for the children and their families, and the disadvantages and advantages of early intervention services for children with cerebral palsy. The conclusion of this literature and research review also includes recommendations based upon the literature and my personal work in home intervention. The paper concludes with a description of future research needed in the area of early intervention services and children between the ages of birth and five years old diagnosed with cerebral palsy.

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CHAPTER 1

Introduction

Introduction

Parents are a child's first teacher. Parents and families have resources available to enhance their child's development if they choose to utilize the resources. Families with children of special needs have additional resources to assist in giving their child the quality of life a typical child and family may have. Families may not have the experience with children of special needs including knowledge about the specific diagnosis and available resources. "There is growing evidence that early intervention services have a positive influence on the developmental outcome of children with established disabilities as well as those who are considered to be at risk of disabilities" (Council on Children with Disabilities, 2007, p. 1153).

Home Intervention services are a resource for families and children in need of services for various reasons. Services are provided at the convenience of the family in the home. Early intervention services are for children from birth to three years old who are at risk due to drug exposure, have developmental delays, or medical conditions. Depending on the circumstances of the situation, a family and/or child may or may not be eligible for home intervention services. According to the Individual with Disabilities Education Act (IDEA) "infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B" (Building the Legacy:IDEA 2004, 2004, para. 2).

Children need to have a reason to be eligible for services under Part C Special Education. Eligibility for Part C Special Education can vary by the state where a family resides. In the state of Iowa, there is a program called Early ACCESS through which children birth to three years old are able to receive home intervention services if they are eligible. To be eligible for Early ACCESS, a child needs to be under the age of three years, show a delay in one or more developmental areas greater than twenty-five percent (a delay of twenty-five percent is calculated by using a child's developmental age divided by the child's chronological or actual age), possess a medical condition, have experienced a drug exposure, and/or have a high probability for developmental delays (Early ACCESS Procedures Manual, 2011).

Early ACCESS services are play based therapy carried out in a home setting where services providers assist families and caretakers in understanding child development, work on goals specific to each child, and provide support to the family. Individualized Family Service Plans (IFSP) are specific to each family's needs and consist of evaluation information, goals, and services available to the family. Frequencies of home visits vary by service provider, need of the child, and family input.

Parents as Teachers is another home intervention program available to families and children. This program started in Missouri as a pilot program in 1981 and since then"has expanded to all 50 states and seven other countries" (Parents as Teachers: History, 2010, para. 5). The goals for the staff of *Parents as Teachers* are to "increase parent knowledge of early childhood development and improve parenting practices, provide early detection of developmental delays and health issues, prevent child abuse and neglect, and increase children's school readiness and school success" (Parents as Teachers: Results, 2010, para. 2). *Parents as Teachers* personnel train parents to complete their own health and development screening, and offer home visits to families one or two times per month depending on the need of the family. This program also works closely in providing services and referring families to other available community resources.

Home Intervention varies across the world in what is provided for families, how it looks, and what the process is. Christine Bonnier (2008) discusses programs called *Newborn Individualized Developmental Care and Assessment Program* in Sweden as well as the *Infant Health and Development Program* located in the United States. These two home intervention programs are specialized for low-birth weight infants, who are at risk for neurodevelopment issues. The programs described in the study differ from other home intervention programs because low birth-weight and neurodevelopment issues are the only eligibility factors. These specific programs are unlike the Early ACCESS program discussed in this paper because Bonnier (2008) is only accepting children with a risk or diagnosis of Cerebral Palsy. In other programs, including Early ACCESS, many different factors affect being eligible for home intervention.

Many people provide service for children in need of early intervention. A child with a developmental delay in the area of cognitive skills is usually visited by an Early Childhood special education teacher in the home. Within the Early ACCESS program in Iowa, speech pathologists are involved with children who have communication delays. A physical therapist and occupational therapist provide treatments with children for large and small motor delays, as well as the occupational therapist assisting in feeding concerns. A diagnosis that usually calls for all service providers mentioned above is Cerebral Palsy.

Description of Topic

Cerebral Palsy is defined as "a group of disorders of movement and posture causing activity limitation attributed to a static disturbance in the developing brain, often accompanied by associated impairments and secondary health conditions" (Damiano, 2009, p. 1200). Cerebral Palsy is the most common condition treated by pediatric physical therapists (Bartlett & Palisano, 2000). Risk factors for Cerebral Palsy (CP) vary with each child. Risk factors included prematurity in the study by Larroque et al. (2008) which included five year old children in Europe who were born before 33 weeks gestation. In this study of 2,357 children, 159 children were diagnosed with Cerebral Palsy. In another study, "the presence of a lesion of the brain or other factors may indicate that infants are at risk for CP" (Heilkema et al., 2010, p. 1471). In pediatrics, Heilkema et al. (2010) stated that Cerebral Palsy is a common physical disability amongst children. Maternal health and child illness are two risk factors for children being diagnosed with Cerebral Palsy. Cerebral Palsy is also more likely in boys than girls, as discussed in the Larroque et al. (2008) study. Thyroid problems, infections, or seizures that affect the mother during pregnancy could be risk factors for a child in being diagnosed with Cerebral Palsy. Infants who are born premature, at low birth-weight, breech, or are multiples have a higher risk of the diagnosis (Understanding CP—the Basics, 2011, para 4). Bacterial and viral meningitis and severe or untreated jaundice are also included in risk factors for CP (Understanding CP—the Basics, 2011, para 6-7).

Options are available for treatment involving children with Cerebral Palsy. Children with CP are entitled to early intervention services through part C of IDEA. If children are between the ages of birth and three years old, service providers can assist the family and child during home visits. Hospital services are available for children as well. Doctors, physical therapists, occupational therapists, and speech/language therapists are the service providers in the hospital setting. When examining home intervention services for families and children with CP, the outcomes, interventions, and frequencies may vary depending on the severity of the child's needs, family need, and unfortunately, schedules of family and service providers.

Rationale/Purpose

The purpose of this literature review was to become more aware of how Cerebral Palsy affects young children, and to understand the advantages and disadvantages of Home Intervention services for children with Cerebral Palsy, specifically between the ages of birth and 3 years old. In this particular review, I focused on children between the ages of birth and 5 years old in order to access more studies in various countries. I wanted to do this review because of my involvement in Iowa's Early ACCESS program as a Home Interventionist for children with special needs. I was especially interested in focusing on the diagnosis of Cerebral Palsy. Within my case load of 18 children, I have two children who were diagnosed with Cerebral Palsy by the age of two. Both children were born into families who have chosen different routes in assisting and advocating for their children. This resulted in variance in the level of service and care between the two families. It has been an eye opening experience working with two separate families and their children who have similar diagnoses, but varying responses to that diagnosis. As a new teacher at the time, I had limited experience in working with children with Cerebral Palsy, so developing this review has been a learning tool for me while assisting families and reading literature about the variation in intervention services.

Importance of Review

I believe it is important for educators to understand the reasons for early intervention services assisting families and children who live with Cerebral Palsy. It is vital for us to be informed of Cerebral Palsy and the effects on young children, as well as families and service providers involved with the children.

In my experiences in providing services for children with Cerebral Palsy, it has been interesting to assist different types of families. This is why the question of effectiveness of home intervention arises. Two families that the Area Education Agency (AEA) has served in this situation have received all available services, including developmental services, speech, occupational therapy (speech and fine motor), and physical therapy. Each family has handled their situations differently. For example, one family flew their child to China for one month to receive stem cells, since the United States does not allow this procedure to be done. This family also receives AEA services along with home healthcare services from a hospital. In addition this family drives 90 minutes three times per week to receive services at a well-known hospital. The second family receives services only from the AEA, which include developmental interventions (cognitive and learning), speech therapy, occupational therapy, and physical therapy services. All services are supposed to be held two times per month, but this rarely occurs for this family because of family scheduling conflicts. Doctors at a well-known hospital also have difficulties in meeting the family for check-ups and visits because of this scheduling problem.

It is important to consider the families mentioned above because of the intensity levels of treatment each family chooses to provide for their child. There are many options available for families with children diagnosed with Cerebral Palsy, and it is interesting to know how the intensity of therapy works out for the child. What is the child's response to the intensity? How does the family cope with the travel, therapy, and providing a *normal* life for their child and family members? By working with these two families and reviewing research, I wanted to learn about the intensity of interventions provided for the children; types of interventions provided for the children, and how to better serve the families on my case load by learning about home intervention services worldwide.

Terminology

This section will provide a list of terms used in this review. For the purposes of this paper, I have defined these terms in the following way:

AEA- Area Education Agencies (AEA) are regional service agencies in Iowa, which provide school improvement services for students, families, teachers, school administrators and their communities. AEAs provide special education support services, media and technology services, a variety of instructional services, professional development, and leadership to help improve student achievement.

Assistive Devices-"tools designed to improve disabled people's physical functioning or reduce the environmental barriers that impede these people's achievement, subsequently increasing their independence, participation opportunities and quality of life" (Sugden & Beveridge, 2008, p. 130).

Cerebral Palsy- "A group of disorders of movement and posture causing activity limitation attributed to a static disturbance in the developing brain, often accompanied by associated impairments and secondary health conditions" (Damiano, 2009, p. 1200).

Cognitive- "pertaining to the mental processes of perception, memory, judgment, and reasoning, as contrasted with emotional and volitional processes" (Dictionary.com, 2011).

COPCA- "Coping with and caring for infants with special needs," a program associated with better developmental outcomes for infants at high risk for developmental disorders (Hielkema et al., 2010, p. 2)

DTP-" distance training package promoting physical, daily, living, speech and language, and cognitive skills" (McConachie, Huq, Munir, Kamrunnahar, Akhter, Ferdous, & Khan, 2001, p. 2).

Early ACCESS- Iowa's system of early intervention services for infants and toddlers with or at risk for developmental delays (EarlyAccessIowa, 2008, para. 1).

Early Intervention- "educational and neuroprotection strategies aimed at enhancing brain development" (Bonnier, 2008, p. 853).

FCP- family centered practice- "supports the increased use of home programs as a strategy for achieving desired outcomes" (Novak & Cusick, 2006, p. 251, 281).

IDEA (Individuals with Disabilities Education Act)- "Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B" (Building the Legacy: IDEA 2004, 2004, para. 2).

IFSP- Individualized Family Service Plan: a plan written for families and children to record what services will look like, who will be involved, the child's developmental information, and goals that will be addressed (EarlyAccessIowa: What is Early Access?, 2008).

Nervous system- "system of nerves in a human, including the brain, spinal cord, and nerves" (Dictionary.com, 2011).

Neurodevelopment- "the development of the nervous system" (Dictionary.com, 2011).

Parents as Teachers- "The trusted resource providing a proven home visiting model for the most respected organizations and professionals who serve the evolving needs of families" (*Parents as Teachers*: History, 2010, para. 5).

Perceptual-motor intervention- intervention occurs in a "pediatric outpatient setting", time spent with a therapist and child, modeling for the parent, focused on child-initiated movement to guide the child (Harbourne, Willet, Kyvelidou, Deffeys, & Stergiou, 2010, p. 1883).

Spasticity- "unusual tightness in the muscle tone" (Cooley, 2004, p. 1108).

Thyroid- "a gland that secretes hormones that regulate growth and metabolism" (Dictionary.com, 2011).

Research Questions

I developed three questions for my review of Home Intervention and Cerebral Palsy in early childhood. This paper is designed to answer those questions, which are the following:

1. What types of home interventions are used with children diagnosed with Cerebral Palsy?
    a. What is the recommended frequency of home intervention services for children with CP?
2. What are the possible disadvantages of home intervention services for children with Cerebral Palsy?
3. What are the possible advantages of home intervention services for children with Cerebral Palsy?

CHAPTER 2

Methodology

In this chapter, I define the search parameters I used to locate appropriate research about Cerebral Palsy in young children, as well as the kind of services they receive at home. This chapter includes how I located my resources used for review, how I selected resources based on my criteria, and whether I had limitations and delimitations in searching for resources.

Location of Sources

The main sources of information for this review included using ERIC, PsycINFO, and Education Full-text by searching within the Rod Library online system. To obtain articles for the review, I used the keywords: *early intervention, Cerebral Palsy, home intervention, early intervention* and *Cerebral Palsy, home intervention* and *Cerebral Palsy, Cerebral Palsy* and *early childhood.* By using these keywords and finding sources of information, I was able to find information in the health and medical fields that fit my search. This path, then, led me to use Google Scholar to locate additional resources. The Burlington, Iowa, Public Library contained many books used in the review; these books introduced the basics of Cerebral Palsy and assisted in defining terms used in special education.

Another method used for locating information was personal communication with families that are experiencing life with a child diagnosed with Cerebral Palsy, especially their involvement with early home intervention. I have been in contact and working with each family for two years. One family has been receiving Early ACCESS services, made a visit to China for stem cells, and works with two hospitals and home healthcare for therapy. The other family has only been receiving Early ACCESS services for therapy.

Selection of Sources

In my search for resources, I stayed within the past 10 years, to make sure I was using up-to-date information. I consider this a limitation because when I searched there were reviews pertinent to the topic, but they appeared to he out-of-date. I also limited my search to research studies of children between the ages of birth and five years old with or at risk of Cerebral Palsy rather than relying on essay-type or theoretical articles.

There were many articles that I could not access for various reasons. Some sources only provided article abstracts. Others were not accessible without specific permission or required purchasing copies. This was a limitation to the review because I felt that the titles and abstracts were reliable sources of information, but I was unable to access the full text articles.

Criteria to Include Literature

For my paper, a set of criteria was included for the review. Criteria included: 1) research was limited to studies within the last 10 years, 2) research studies used were full-text from peer-reviewed journals and books from public libraries, 3) participants in the study needed to be between the ages of birth and five years old and at high risk for or diagnosed with Cerebral Palsy, and 4) articles addressed issues around home intervention and its success.

Limitations/Delimitations

A delimitation in searching for research articles was that I had to change my search parameters because Early ACCESS services are only involved in Iowa; therefore I had to broaden my search to include various early intervention services for supporting young children with Cerebral Palsy. Once I did this, I was able to find many articles involving early intervention services and Cerebral Palsy. I found some resources including early intervention in other countries. Christie Bonnier (2008) discussed early stimulation programs in Sweden and the same type of program in the United States. A review by Novak and Cusick (2006) discussed home programs specifically dealing with occupational therapy in Australia for children with Cerebral Palsy. Many studies were completed in other countries such as Australia, Bangladesh, United Kingdom, and Sweden, as well as the United States.

Another delimitation in this review is the age level for which I expanded my review. By reviewing studies in home intervention and Cerebral Palsy, I focused on children from birth to five years old. Early ACCESS is only from birth to age three years old. I included birth to five years old in this review because children generally are not diagnosed with Cerebral Palsy until they are around two years old. Because I included up to age five, this gave me more study results in order to answer the research questions I had developed.

Procedures to Analyze Sources

Before locating articles, I defined the list of research questions. When I located articles and books, I read each article and wrote notes I thought would be beneficial, keeping in mind my research questions. I labeled each article I selected with which research questions were being addressed. I compared and contrasted the findings of the studies, sorting the documents into piles to visually show me what research questions were being addressed more than others. I used this information to continue my search in more detail to address all questions. I gathered information about the participants involved, ages, results, and discussions within each article. Qualitative research articles were sought in order to gain insights on the concerns and attitudes towards families and children with Cerebral Palsy and home intervention. The quantitative research was used in order to determine the results achieved in groups of children in relation to the severity of their needs compared with the outcomes of different interventions.

CHAPTER 3

Literature Review

Developing a review of research will assist educators and families in understanding the effects of home intervention services and Cerebral Palsy. This review of research will help educators understand how early intervention works and gain a knowledge of what some of their students may have been involved with at a young age. Families will benefit from this review of research by gaining the knowledge of what services can be provided for their child with special needs and understanding the importance of family involvement. This chapter will answer my three research questions:

1. What types of home interventions are used with children diagnosed with Cerebral Palsy?
   a. What is the recommended frequency of home intervention services for children with CP?
2. What are the possible disadvantages of home intervention services for children with Cerebral Palsy?
3. What are the possible advantages of home intervention services for children with Cerebral Palsy?

Types of Interventions for children with Cerebral Palsy

Coping with children with special needs is difficult for any family. Families in this situation need support from others in order to know and provide what is best for their children. Specifically, a family who has a child with Cerebral Palsy should be informed and aware of services that can be provided for assistance in the well-being of the child and for the family. There are many services available to families (as outlined in Chapter 1 and described throughout research reviewed in this chapter) that are age appropriate, although the family has to decide which suits them the best.

Types of intervention vary by the geographic area. In Bangladesh, for example, there is a lack of trained professionals to assist the growing number of disabled children and their families. A program developed in Bangladesh was called the *Distance Training Package* (McConachie et al., 2001). The study providing the intervention followed 47 children with Cerebral Palsy, aged between 2 and 5.5 years, over a period of 18 months. The study took place at two different outreach centers: rural and urban. There were 24 children that attended the urban center and 23 children that attended the rural center. In this type of program, "parents are trained for 1-2 hours on each occasion of contact, and take home pictorial manuals as a reminder of activities" (p. 2). Throughout the training sessions, the trainers are involved in demonstration, teaching, and observing the mother handle the child with the ideas and activities given. In this particular study, mothers were the only parent to participate. Out of the 24 children attending the urban center only eight children attended monthly, eight children came between three and seven times, and eight children attended one or two times. In the rural center, 11 children attended all the suggested sessions. The study determined that attendance in each center was based on many factors. Parents reported problems with distance and traveling expenses, but the research team decided that further research should be done with a larger sample size to determine more accurate results.

In Sweden, Nordmark, Hagglund, Pedersen, Wagner, and Westbom (2009) carried out a study on 359 children from two to fourteen years old with Cerebral Palsy. The study was done to track the decreasing range of motion because of muscle deterioration, a common problem in children with Cerebral Palsy. The children were observed and assessed by a physiotherapist two times per year until they were six years old and then one time per year until age fourteen. By doing this type of intervention on a large sample in southern Sweden, the researchers found that there was a "decreasing mean range of motion over the period 2-14 years of age in all joints or muscles measured" (p. 1741). The authors were focused on this geographic area because they wanted to gain knowledge of child development in a total population to plan for future health care programs. This study focused on a different area than other studies in that the researchers wanted to know what programs to develop for the children based on families' needs.

LEARN 2 MOVE is part of a current Dutch national LEARN 2 MOVE research program that involves families and children from birth to five years old (Hielkema et al., 2010). The LEARN 2 MOVE program is a research group that evaluated the new intervention program called COPCA, Coping With and Caring for Infants with Special Needs, which is a family centered program to assist families in educational and motor goals with their children. "The physiotherapist, called coach, listens, informs and observes while the caregiver is involved in daily routines with the child, including play, thereby creating a situation in which caregivers feel free to explore and discuss alternative strategies" (p. 3). In this study, forty infants at severe high risk for Cerebral Palsy were recruited. Participation was voluntary, and the intervention period was designed to last twelve months. Since this study has only been going on since 2010, the authors have noted that it is still in progress. What the researchers aim to assess is whether this COPCA approach is beneficial for infants at risk rather than the current interventions they may be already receiving. Data suggested that the interventions taking place have had a positive effect on all areas of development due to increased parent interactions.

Iona Novak and Anne Cusick completed a study which involved occupational therapists working with children with Cerebral Palsy and their families in the home setting in the United

States. This study involved twenty-eight home programs which varied in both frequency of interventions and the severity of the diagnosis of the children involved. This means the study consisted of twenty-eight different settings within the United States in which Novak and Cusick researched the frequency of interventions and each child's needs that are diagnosed with Cerebral Palsy. Novak and Cusick researched home programs for children with Cerebral Palsy through articles and their own experience. Their study focused on *Family-Centered Practice (FCP).* This "approach shifts service focus in pediatric health care away from professionals determining children's needs within institutional care settings, towards parents, being recognized as central and expert caregivers" (Novak & Cusick, 2006, p. 251). Their study was designed to answer questions relating to the characteristics and intensity of the home based programs. The researchers' review of literature only included 28 articles about family centered practice indicating that "there was little to assist occupational therapists to design, implement, or evaluate home programs" (Novak & Cusick, 2006, p. 253). Although home based programs are a type of intervention for children with Cerebral Palsy, it may be noted that there is not significant research to show how these programs are used in the delivery of early intervention services.

Similar to the *FCP* study introduced by Novak and Cusick (2006), Ketelaar, Vermeer, Helders, and Hart (2000) were interested in parental involvement and studied the *Portage Project.* This project consisted of high parent involvement where "parents were trained to teach their children certain [not described] skills, so the child is being taught in his or her natural environment and by the people who are able to provide the greatest continuity of care" (Ketelaar et al., 2000, p. 111). This research compared two groups. The first group consisted of twenty-five mothers of children with Cerebral Palsy who were doing intensive physical therapy. The second group consisted of twenty five mothers of children with mental retardation who were stressed from having to do therapy with their child. The groups varied in their involvement with therapy. In the first group, each mother was available to assist in intervention services five days per week, four hours per day. In the second group, the mothers were not involved in intervention services with their child. These services were only performed by the professionals involved. The authors failed to mention how long their study took place. After the study ended, it was determined the first group of children met their goals faster than the children only working with the therapists. It was noted the parents who did the therapy and were involved with their children gained more confidence and learned better ways of coping with their child's behaviors. The researchers strongly suggested throughout the study that parent involvement was the reason for the child making gains during intervention services. While the kinds of intervention varied in this research study, so did the number of interventions, which is related to the next section on frequency of interventions.

Frequency of Interventions provided for children with Cerebral Palsy

In my experience, frequency of interventions provided for children with any special needs varies by service provider. It appears that the more frequent the intervention, the more progress we see from the child as well as involvement with the family. In doing this review of research, it was important for me to understand if there is a relationship between frequency and progress of a child with Cerebral Palsy.

Orton, Spittle, Doyle, Anderson, and Boyd (2009), in a separate article focusing on the correlation between preterm infants and high risk factors for Cerebral Palsy, discussed early intervention programs in Australia. Other risk factors mentioned in the study were cognitive, motor, and behavioral problems. In this study, there were 2,686 infants involved in early developmental interventions after hospital discharge. This study followed the infants from birth to school age. The authors discussed more in depth the frequency of interventions, stating that "it may be expected that dose and compliance are associated with the effectiveness of the intervention" (Orton et al., 2009, p. 857). The term, *dose,* refers to the frequency of interventions of the infants in the group, while, *compliance,* refers to the consistency with which families were involved in the interventions. Part of the criteria within this study included "early intervention that aimed to improve cognitive or motor outcomes, performed at home, hospital, or in a community center" (Orton et al., 2009, p. 852). The services were provided through the hospital where interventions included physical therapy, occupational therapy, psychology, neurodevelopmental therapy, parent infant relationship enhancement, infant stimulation, infant development, developmental care, or early intervention. By the end of the study, the researchers concluded that "early developmental interventions have a positive short-term effect on the cognitive development of preterm infants, but these benefits are not seen at school age" (p. 854). This was determined because the study followed the children from birth to school age. To assess the children at an older age, an IQ test was administered which demonstrated little evidence to suggest the "intervention had a beneficial effect on cognitive development" (p. 854). It was mentioned in Orton et al. that their research intervention may have a limited effect on children as they age. This may be difficult to claim since the children were not given an IQ test at diagnosis or entry into the research study.

Frequency played a factor in the next two studies discussed in providing services in Bangladesh. The first study described the *Distance Training Package* in which training was limited to those mothers who could return to the center on a regular basis. This study involved 47 children over an eighteen month period. In the urban center, training was available five days per week, while it was available only one day a week in the rural center. Attendance by the mothers played a factor in the result of the program, and it was found that "repeat attendances were more likely where mothers reported higher stress" (McConachie et al., 2001, p. 6). Frequency varied in this situation because of attendance and service providers were not sure when they would see the mothers or children next. The researchers stated that "where the service can evolve to be more home-based, or at local centers, then it will become easier to focus on a particular set of appropriate short-term goals decided upon the consultation with parents" (McConachie et al., 2001, pp. 8-9).

The second study from Bangladesh examined the frequency and intensity of treatment on gross motor functions for children with Cerebral Palsy. Tsorlakis, Evaggelinoi, Grouios, and Tsorbatzoudis (2004) studied 38 children from three years to fourteen years old who were divided into two groups. The children involved did not have any other therapy involvement except for physical therapy provided within this study. Group A received therapy two times per week for fifty minute sessions and Group B followed a more intense program of five days per week with fifty minutes per session. The groups were involved in therapy for sixteen weeks. Four children dropped out because of various concerns and surgeries. After the sixteen weeks and the final assessment, the data suggested that gross motor skills increased significantly for both groups based on frequency of treatment. Overall, Group B performed better and showed significant improvement over children in Group A. The authors of this study reported that the increase in motor skills could have been because of maturity and not therapy. Further studies regarding the intensity of intervention for children with Cerebral Palsy should be studied in order to fully understand and interpret intensity of services provided.

As intervention programs were developed and implemented, it appears the frequency of therapy not only depends on the needs of the child and family, but also the program that is involved. Bonnier (2008) found that the results were better with the long term programs based upon parent support. "Programs targeting patients with Cerebral Palsy have produced inconclusive effects" (Bonnier, 2008, p. 855). The COPCA program mentioned earlier in chapter 3 provides interventions once a week during a year (Hielkema et al., 2010, p. 3). This study has been ongoing and it has yet to determine whether the frequency of one home visit per week is beneficial to families. The researchers' goal is to "assess whether the COPCA approach is more beneficial for infants at risk for Cerebral Palsy and their families than current interventions and to get insight in the working mechanisms and effective components of early interventions" (Hielkema et al., 2010, p. 6).

DeLuca, Echols, Ramey, and Taub (2003) completed a single child study on Pediatric Constraint-Induced Movement Therapy. Constraint-induced movement therapy was first designed to use in patients who have had a stroke. It included daily intensive training to encourage increased and improved movements and restraint of the less impaired, meaning they would restrain the healthy body parts, to help force the patients to use their weaker body parts. This type of therapy is used to help patients strengthen the body parts that are difficult to use. In this case, a 15 month old child who was born at 28 weeks of gestation was diagnosed with Cerebral Palsy at four months old. As we remember from prior research, it is uncommon to be diagnosed at such an early age. The child began receiving services two days per week, including physical, occupational, and speech therapy, along with special education, nutrition, and nursing services. At 15 months of age, the child began services daily for six hours with a primary therapist and a graduate psychology student; the child was also involved with a pediatric therapist who performed play-based and functional activities. All activity took place within the child's home environment. Results suggested that after intensive six hour per day therapy for three weeks, the "child developed new behaviors throughout the interventions" (p. 1003). Throughout the interventions, the child was able to reach for, grasp, and release objects, assume weight bearing positions (positioned prone on elbows), make gestures, self-feed, sit independently, and increase interactive play.

In this study by DeLuca et al. (2003), data suggested that the type of therapy and frequency played a factor in the improvement of the 15 month old child. Credit was given to the relationship the child had with service providers, as well as parent involvement that promoted what was done during the time the service providers were in the home. The researchers noted that future interventions need to involve a larger sample size, cost-benefit ratio, and "whether the benefits of short bursts of intensive therapy as given would be more cost beneficial and produce greater intervention effects than when given at traditional dosage levels" (pp. 1012-1013). It would also be important to note the differences in family involvement and compare involvement in each family with the outcome of the intervention. As other studies have mentioned, I believe parent involvement is crucial. The intervention frequency and intensity provided in the DeLuca et al. study demonstrates that families' thoughts and schedules need to factor into determining whether or not their intervention is effective.

A study was done to compare interventions for 35 infants less than two years of age, with an average age being 15 months. The infants, all with Cerebral Palsy, were randomly assigned to a home program or perceptual-motor intervention program carried out in an outpatient pediatric setting (Harbourne et al., 2010). Within the comparison of interventions, the children involved in the home program were seen one time per week for eight weeks, while the children in the perceptual-motor intervention were seen two times per week for eight weeks. The interventions were completed by physical therapists to note progress on improving sitting postural control. The study was designed so that if a child missed a scheduled session, the session was rescheduled as soon as possible to encourage continuous progress. Therapy varied in each setting due to the resources available. In the home setting, therapists focused more on routines of the child and daily living, while in the outpatient setting, the child and therapist were directly involved in physical exercises. The duration of each home or outpatient visit was one hour each session. Even though crawling was not a priority in this study, the authors did report that "twenty percent of the infants in the home program group crawled by the end of the interventions whereas forty percent of the infants in the perceptual motor intervention group crawled" (p. 1890). The targeted focus area in this study was sitting which was specifically practiced during each visit of the eight weeks. The data showed that from pre to post intervention the average change in scores was "twenty percentage points, which is greater than expected for simple maturation in a child with CP during that time period" (p. 1893). The authors noted that "it was the skilled attention to the specific task rather than the frequency or method of intervention that provided the functional change" (Harbourne et al., 2010, p. 1893). This statement was important to note because other studies that were reviewed did not specifically mention the task, but focused on the frequency or method of intervention. A limitation that was brought up in this study was the difference of dosage between the home program and perceptual-motor intervention. DeLuca et al., (2003) and Hielkema et al., (2010) have shown an increase in attaining progress goals due to an increase in treatment frequency while this study focused on the type of intervention rather than the frequency of the intervention provided.

Novak and Cusick focused on family-centered practice which consisted of home based programs. As mentioned above, there is not a significant amount of research done on the family-centered approach, but by reviewing this research, frequency can be measured in a variety of ways. Because Novak and Cusick (2006) found little research on home based programs, they developed a model starting point suggesting five phases of action for "tasks and concerns that need to be addressed in home programs as they develop" (p. 260). One of these focus areas included implementing the program at home (Novak & Cusick, 2006, p. 261). This area discussed the support strategies and frequency of working with the child and family. What the researchers considered to be a part of frequency was "families should be able to contact the therapist for support as they see fit: usually by phone and if needed with follow-up face to face contact" (Novak & Cusick, 2006, p. 261). The researchers concluded that frequency is not only the number of times a service is provided per week or month, but how frequently a person outside the family is being used as a resource, whether it is a phone call, email, or some other form of contact.

In this section discussing frequency, I have learned that frequency may not be as important as the intervention that is provided. Frequency can be described as the specific task at hand rather than how many times the task is being completed. I found that doing this review of research, the specific task that is implemented with each child and how it is performed is more beneficial to the child and family rather than how often it is performed. If we find the right task and intervention for the child, this may be as beneficial to the progress of the child's outcomes as how many times we are performing the task.

Disadvantages to early intervention services

Time

Time is a factor in various ways within families for children with special needs. One way that time has been an issue is in determining when early identification occurs for children with delays in development. In the National Early Intervention Longitude Study, it was found that age at first concerns for a child with a diagnosed condition was around two and a half months of life, while age of first concerns for children at risk, such as prematurity, was around two months of life (Council on Children with Disabilities, 2007). This means that concerns did not begin to arise for children until two and a half and two months respectively. It took this long for children to exhibit delays or concerns in development, therefore services are not provided until delays or concerns are shown. While this information was shared, this study also found that children and families waited even longer to receive services or develop an IFSP (Individualized Family Service Plan). While it took two and a half months for concerns to arise in children with a diagnosis, typically they did not begin receiving services until around seven months of age. For children with at risk conditions, services typically began around five months of age. Time appears to be the issue because it takes time to develop the IFSP which is important to complete before services begin.

In nearly all families, time constraints take place, whether it involves getting children to school, keeping appointments, or maintaining work schedules. In a study discussing play based stimulation for young children with Cerebral Palsy, mothers who participated reported that "time was a major constraint and that attending the center helped them in maintaining a fixed schedule" (Gupta & Bhargava, 2008, p. 119). Only six infants and their mothers from India were enrolled in this sample. The children in this study ranged from two and a half years old to five years, and their mental ages ranged from eight months to two years. Time was an issue for mothers because the mothers needed more effective methods on how to implement activities with their children. It appeared throughout the study that a mother's expectations did not match the child's present or future performance; therefore the mothers found it beneficial to learn how to foster their children's independence through learning various methods for each intervention. The location of intervention in this study varied due to the combination of home visits and center visits. The center consisted of the family bringing their child into a different environment to work with the therapists, while the home visits consisted of the therapists going to the families' homes.

Time is also an issue in any care for children with special needs, and especially for children with Cerebral Palsy. Carl Cooley (2004) discussed time being a constraint for families and care providers in regard to long term care. Data from the American Academy of Pediatrics in Cooley's study suggested that seventy-five percent of children with Cerebral Palsy have spasticity. Spasticity is unusual tightness in the muscle tone. Because of this, all patients with Cerebral Palsy require daily range of motion exercises with monitoring by a physical therapist. This becomes an issue for families in terms of the location at which the exercises take place, the time it takes to travel round trip, time to do the exercises, and the need to repeat this every day. Cooley also discussed the extra time needed for feeding and providing adequate nutrition; dental visits because of oral motor tone, tongue movements, breathing, and drooling; and the extra time for all regular office visits for management of the child's general physical condition. Caregivers are involved in every step and the family's role is crucial. Cooley (2004) found that "as adults, most continue to live in community settings, but one third live at home with their parents, whose ability to continue care giving may decrease as they age" (p. 1111). It is important to note that in his research, he found that twenty percent of adults with Cerebral Palsy are ambulatory, forty percent can walk with assistance, and the remaining forty percent are nonambulatory. Because of the physical conditions, it appears that time and assistance for children with Cerebral Palsy is a lifetime factor that interventions may or may not be able to improve. Time is crucial for families and children in figuring out what works best for them.

Novak and Cusick noted that additional research is needed on the effectiveness of home based programs for children with Cerebral Palsy. A disadvantage for parents appears when not all providers understand how to implement home based programs and what works best. It is important to note that "home programs need to be sensitive to family direction, daily routines, resources, as well as the attributes of the child and the potential capacity of the family to enhance competency for caring" (Novak & Cusick, 2006, p. 252). In other words, home programs should be cautious of the family and their home, making sure to understand that service providers are not in control of a family's home while they are there. Service providers need to be aware of the family and their situation to assure they fully understand the life of the child and family. If the family seeks out early intervention services, assistive devices can be sought to enable the child to function better in the home environment. Huang, Sugden, and Beveridge (2008) formed a study to discuss assistive devices for children with Cerebral Palsy. In this study, there were fifteen children and their mothers involved. This study was designed to evaluate the use of assistive devices in the home that are available to the families. Assistive devices were explained by Huang et al. (2008) to be tools that are used to improve a person's life and functioning. The results of this study suggested "low frequency of device use at home by participating children" (Huang et al., 2008, p. 130). To be a provider in homes, an interventionist needs to be aware of the home situation and know that it varies with each place they would visit. Besides the lack of research about home programs, there is a lack of knowledge among professionals about how to implement home programs, decide on procedures, and to prepare for the adjustment of going into someone else's home. This adjustment demands a strong relationship between a provider and the family.

Gupta and Bhargava (2008) found in their study that mothers' "expectations from the infants did not match the child's present or future performance" (p. 118). Mothers reported that even though they approached doctors and professionals, a lot of information was shared by the medical providers that parents did not understand. This issue was similar to the results in the Huang et al.,(2008), study; that is, the reasons for low use of assistive devices by families were the limited participation of parents to enforce the use and professionals to inform, the lack of information about assistive devices, the need for follow-up services, and the need for regular training for families. The disadvantage of the families not understanding what their providers are saying reduces their ability to address the condition of the child in their own home. The lack of understanding leads to lower parental involvement and therefore lack of progress in a child's outcomes.

Another disadvantage had to do with the study by Hielkema et al. (2010). Within this study, the researchers called for more research to determine which interventions to actually hold with the family and how they assist in a child's development through daily life. The authors mentioned that "little evidence exists that current interventions are effective in optimizing daily life functioning" (Hielkema et al., 2010, p. 1). Because of the lack of research noted within this study, the authors were unable to determine how effective the interventions are for the child and family.

Cost

A disadvantage to some early intervention services for families is the cost of these services. Barlett and Palisano (2000) looked at the effectiveness of intervention based on various factors such as the child's characteristics, family ecology, and health care services. This study looked at data-based model and the dimensions of human functioning such as child characteristics, family ecology, and health care services. Through this research, the authors determined that payment for health care for early intervention could be a challenge both for families and service providers working with children who have Cerebral Palsy. Cost was determined to be a challenge for service providers because of insurance reasons. If the insurance was not paying for services, the service providers were not able to go into the home because they were not getting paid. Families and service providers are in a bind because families need the services for their child, but service providers are struggling with the desirable cost/benefit ratios. Carl Cooley (2004) reported that "each new case of Cerebral Palsy involves an average lifetime cost of $503,000" and the expected life span is 30 years (p. 1106). In Cooley's survey taken by 33 children with special needs and their parents, access to a care coordinator and coordination among health care professionals were areas of dissatisfaction. Forty-eight percent of the families surveyed reported that one or more services, including physical therapy, were not covered by their health plan, and were too expensive to cover on their own. I believe it would be critical to expand this study to a larger sample of families. If cost is the main factor of making services accessible and available to families, then as service providers we should look for the alternatives. There are services available in the state of Iowa, such as Early ACCESS for children up to age three, and Parents as Teachers is available in other places, but families may not be aware of these services or what is available in other states or countries that are at no or little cost to the families.

Advantages to early intervention services

MRI and Diagnostic Technology

In many articles that address Cerebral Palsy, very low birth-weight infants are mentioned because this is a risk factor for Cerebral Palsy. Research was conducted in whether or not a neonatal Magnetic Resonance Image (MRI) would be able to predict the neurodevelopment outcomes of preterm infants. Having an MRI done on children is a precaution to determine whether preterm infants would need some sort of services. Woodward, Anderson, Austin, Howard, and Inder (2006) reported that "abnormal findings on MRI at term equivalent in very preterm infants strongly predict adverse neurodevelopmental outcomes at two years of age" (p. 685). In other words, it appears that preterm infants are more at risk for cognitive delays than a child who was born full term. Within this study of 167 very preterm infants, 17 percent had severe cognitive delay, 10 percent had severe psychomotor delay, 10 percent had Cerebral Palsy, and 11 percent had neurosensory impairment (Woodward et al., 2006). The MRI compared the individual children's white and gray matter abnormalities as very preterm infants and again when they had reached their second birthdays. Throughout the study, "our findings suggest that the identification of early cerebral abnormalities with the use of the MRI should offer a valuable complement to other neonatal and psychosocial risk factors in improving the identification of preterm infants at high risk for subsequent neurodevelopmental impairment" (Woodward et al., 2006, p. 693). This study was advantageous in identifying the infants that were at risk for Cerebral Palsy

Parent Involvement

The Woodward et al. (2006) study also described another potential advantage of home intervention. Understanding that there are resources available at no cost to the family is an advantage, while the disadvantage appears to be that families do not always utilize the resources available to them, depending on their situations.

An earlier study appeared to agree regarding the importance of parental involvement in the development of children with Cerebral Palsy. Ketelaar et al. (2000), described earlier in this chapter, found that intervention programs involving parents "improve their understanding of their children's development and capacities and may help them to develop appropriate expectations for their children's future" (p. 108). Home intervention programs that support parents' understanding of potential services and their child's needs provide a critical advantage to the progress of the child.

Parent participation and family centered programs appear to be important in child development and progress. Gupta and Bhargava (2008) stated that the "most effective agent of intervention in fostering and sustaining development is the family" (p. 114). The "targets of these programs include preservation of the mother-infant relationship and enhanced bonding, stress reduction in the hospital and individually tailored development-enhancing care in neonatal intensive care units" (Bonnier, 2008, p. 854). Long term programs that involved parents showed better results than the short term programs available.

Child Outcomes

The family centered program called COPCA was developed to work on infants' educational and motor goals (Hielkema et al., 2010). Ketelaar et al. (2001) also discussed that "parental participation in intervention programs for children with physical disabilities has become an important issue in recent years" (p. 108). Reviews by Hielkema et al. (2010) indicated "that early intervention programs may have a positive effect on cognitive development of young children, but no or minimal effect on motor development" (Hielkema et al., 2010, p. 2). With this program, the size of "positive effects was the degree to which parents were involved in setting goals for their children's program" (Ketelaar et al., 2001, p. 108). In my experience in working with children who have a diagnosis of Cerebral Palsy, the physical aspect appears to have been more severe in the cases where interventions were sought out by parents. Parents appeared to notice the physical delay of the child easier than a delay in a different developmental domain. This has appeared to be a disadvantage for our service providers working with a child who needed to work on both physical positioning and cognitive outcomes. What our teams of service providers have decided to do is that if the service providers teamed up to go on home visits at the same time, one could work on the physical positioning of the child while the other worked on the cognitive outcome agreed on with the family. In other words, our intervention team has developed a strategy that provides an advantage of dual intervention strategies.

In these two sections discussing disadvantages and advantages, factors were discussed such as time, cost, and parent involvement. Time appeared to be the most concerning factor for families and service providers involved in early intervention services with children diagnosed with Cerebral Palsy. Cost briefly was discussed in that money is involved with the family and service providers. It costs money to provide for a child and if a child has a diagnosis of Cerebral Palsy, it seems the cost rises with medical bills, therapy services, time, etc. Parent involvement was critical in a child's progress and seemed to take on a positive effect for parents in that they understood how to treat their children and involve their therapy in daily routines. All in all, it was determined in looking at the disadvantages and advantages of early intervention services for children with Cerebral Palsy that more research is needed to determine if intervention services are beneficial to families and their children.

CHAPTER 4

Conclusions and Recommendations

The purpose of this study was to review previous research within the topic of early intervention and very young children with Cerebral Palsy. My goals were to become more aware of how Cerebral Palsy affects young children and to understand the advantages and disadvantages of home intervention services for children with Cerebral Palsy and their families. The review included the types of early intervention services for children with Cerebral Palsy, the frequency of services available, and the advantages and disadvantages of these services provided for children and family. Findings for this review were discussed in chapter 3. A variety of intervention programs were found for children with Cerebral Palsy across the world. The frequency at which services are delivered varied depending on the type of intervention. Advantages and disadvantages to each type of intervention were discussed. Many of the research studies conducted suggested that family involvement in children with Cerebral Palsy was critical in the progress of interventions provided to the child. A brief summary of each research question and findings will follow. This chapter will then introduce recommendations for home intervention service providers and parents as well as a discussion of the topics needing further research.

Conclusions

The first question reviewed in this study asked what types of intervention services are available for children with Cerebral Palsy. There appears to be a wide range of services available around the world to the children and families. Although intervention therapy varied for the children, the types of services for children were designed to be more accessible to families. A program called the *Distance Training Package* was developed for families to better meet their children's needs by offering services in the rural and urban areas of Bangladesh (McConachie et al., 2001). Along this same line of family focus, the LEARN 2 MOVE program in the Netherlands became more accessible to families as therapists conducted home visits to administer the interventions. Novak and Cusick (2006) focused their interventions to be more family-centered by shifting their services from hospitals to homes in Australia. The Ketelaar et al. (2001) Portage Project study in Norway involved children and families implementing interventions within their natural environment. While the interventions were more apt to be in a natural home environment for children and families, the frequency of the interventions varied throughout these studies.

The research results for question 1A on the frequency of interventions provided to children and families was mixed, depending on the intervention provided and the involvement of family. Parent involvement in a majority of the studies determined the frequency of interventions provided. Frequency in this study includes access to the professionals whether by phone or visits into the center. Orton et al. (2009) discussed frequency in their interventions based on the compliance of the families with the demands of the service program. Attendance in the *Distance Training Package* study by McConachie (2001) varied because of family involvement. Providers were uncertain when they would see families again because of the rural and urban accessibility to families.

The type of program also factored into the frequency of interventions depending on how often the providers were available (Hielkema et al., 2010). This study was designed to determine if services given one time per week would be effective for children with Cerebral Palsy. More frequency was determined to be beneficial in the case study of one 15 month old child (DeLuca et al., 2003); six hours per day for three weeks demonstrated progress for the child in this study. In another study comparing frequency of interventions for two groups, the group that received services two times per week for eight weeks appeared to show more growth than the group that received services one time per week for eight weeks (Harbourne et al., 2010). Frequency and the type of home intervention provided both appear to play roles in the progress in outcomes of children with Cerebral Palsy.

The final two research questions asked what were the disadvantages and advantages to interventions for children with Cerebral Palsy. Time appeared to be a disadvantage in various research studies reviewed. Gupta and Bhargava (2008) and Cooley (2004) both discussed time as a factor for families. Scheduling becomes a concern for families in arranging for interventions, whether they are provided in the home, hospital, or therapy center. The effectiveness of home based programs was also a disadvantage in that not much research has been done to assist providers in understanding how home based programs are successful for families and children with this diagnosis (Novak & Cusick, 2006). Two studies discussed cost being a disadvantage for families in that availability and access for certain types of interventions may become expensive for families (Cooley, 2004). Payment for services in general posed a concern for families with children who have special needs (Bartlett & Palisano, 2000).

Even though there may seem to be an overwhelming amount of concern due to various factors in interventions for children with Cerebral Palsy, there were advantages noted in the studies. Research was conducted in one study to assist medical staff with low birth-weight infants by using an MRI at birth. This study found that using an MRI was a predictor for whether or not children would need service for Cerebral Palsy later on (Woodward et al., 2006). In multiple studies, it appeared that the more parent involvement, the greater the progress in children's outcomes and services provided to the child. Ketelaar et al. (2001), Gupta and

Bhargava (2008), and Hielkema et al. (2010) all discussed parent involvement, suggesting that the most effective factor in improving a child's development is involving the family in interventions and teaching them how to work with their children between home intervention visits.

Identify and Synthesize insights

As early childhood continues to expand and intervention services continue to be researched and reviewed by educators, it is important to look at the current research and put this into a context that means something to families, early childhood educators, and service providers. In Chapter 3, I reviewed studies involving interventions from all over the world. As an educator, it is critical that I take this information into my own occupation of an Early ACCESS home interventionist and apply this to the families, service providers, and children with whom I work. As I look at how this review of research applies to me, I think of the families with whom I work that have a child diagnosed with Cerebral Palsy. Ketelaar et al. (2001) reported that involving parents will "improve their understanding of their children's development and capacities and may help them to develop appropriate expectations for their children's future" (p. 108). The key point I got out of the review of research is that parent involvement is critical. So often, service providers, including myself, go into the homes and work with the child because it is our job. I realized that I need to look at the whole family during the interventions and learn to understand the family and what their daily life and routines include. By doing this, I can learn to share the interventions that we are doing with the child in the home at that time to assist the family in making those interventions a part of their routine between my visits. Just as important as family involvement is frequency of services provided. Frequency in services varied in each study from six hours per day to a few times per year. In this review of research, I was hoping to get a clear understanding of frequency of services and how frequency may affect the outcomes of the children that have the diagnosis of Cerebral Palsy. This answer did not come clear to me in any study, but I did note the value of frequency in my work. Attending to frequency means that I must have open discussions with the families about what they need to meet their goals, so that I am open to working with the whole family and the individual child at the same time. Frequency is going to vary, just like it did in each study that was reviewed. There is no clear recommendation for frequency of visits that children diagnosed with Cerebral Palsy need. Frequency is something that, unfortunately, depends on family schedule more than the severity of the diagnosis. This review has taught me that in my work, frequency of visits and parent involvement should be considered jointly in providing services for a child in need.

Recommendations

In reviewing research for this particular topic, it was difficult to find specifics on early intervention services and children with Cerebral Palsy. I believe there is a need for more research on the importance of early intervention with young children and this diagnosis. Research should be available for all service providers involved with children with the diagnosis of Cerebral Palsy. Included in this research should be physical therapists, occupational therapists, speech therapists, and teachers. These are going to be the providers available and working with the children from the time of their diagnosis.

Frequency is another area that more research is needed. In reviewing the research found, it was determined that the question of effective frequency was not answered. There were many types of interventions discussed in this paper, but frequency varied by study, provider, child, and family.

Another area needing more research would be the benefits of early intervention services. The disadvantages and advantages section briefly discussed that time and costs are constraints for families. This review of research could be upgraded to add the benefits for children in the future. In order to do that, we would need to increase the age of the child in a longitudinal study to review and note if the child received early intervention services and the child's current capabilities.

Training is needed and should be available to service providers on how to provide services to children and their families. Family involvement is critical when providing interventions and in the daily routines of children with the diagnosis. The language and vocabulary that service providers use with families need to be at a level that various family members can understand. Service providers need to understand that as they discuss an exercise with one family, they may need to use different terms to discuss that same exercise with a different family.

In addition, specific training should be available to service providers on how to work with children in their natural environment, outpatient facility, hospital, or various locations where the interventions may be provided. It is important for the providers to know how to include the family in their interventions since in much of the research, the frequency varied depending upon the type of intervention, family or service provider schedule, and location. Because frequency varied for each child and type of intervention, families should be aware of what constitutes interventions, so they can be a part of this process when the service providers are not present. In the study by Ketelaar et al. (2001), the authors noted that if the parents were more involved in the interventions, they gained more confidence to cope with their child's needs and behaviors.

Training should not only involve service providers, but parents as well. Support groups and educational classes should be available to parents who have children with this diagnosis. In a study by McConachie et al. (2001), high stress levels were noted among parents. Parents should have support groups available to them, so they have an opportunity to ask questions, gather resources for their family, as well as respite services that allow them to rest and think about providing the best life for their child. Several of the studies discussed family involvement in their child's diagnosis, because service providers were more apt to discuss the child and the interventions rather than the overall family and their needs. Service providers may forget that a diagnosis of one child in the family affects everyone living in that household. Service providers need to be a support for both the child and the family.

Future Projects/Research

Research was reviewed involving the frequency of interventions. Since there is not a lot of research done with early intervention services and children with this diagnosis, I would like to continue on with this and involve children on my own caseload. Frequency differs for each child that I work with and it would be interesting to note their progress towards outcomes and family involvement to see if the two are related. In chapter 3, I discussed the study Orton et al. (2009) completed, in which the data suggested that benefits of early developmental interventions are not seen at school age. Additional research might demonstrate that specific interventions are more effective over the long term than others.

Educational Policies

In reviewing research for early intervention services and children with Cerebral Palsy, I have gained more of an understanding on how interventions are provided in different areas of the world. I made the connections between the studies and my own work in providing Early

ACCESS interventions for children with special needs, especially for a few children specifically diagnosed with Cerebral Palsy. Programs like Early ACCESS, *Parents as Teachers*, and programs in Bangladesh, Australia, the Netherlands, and Sweden are working to provide services for children with Cerebral Palsy. In a perfect world, I believe early intervention services for children with Cerebral Palsy should be mandated through an education policy. It is vital for children with Cerebral Palsy and their families to gain this support from various service providers to assist in reaching attainable goals. Currently, I see each state and country having their own system of how to provide for families and children with special needs. Children with Cerebral Palsy have many different needs just in the physical aspect of their life that cost money and time. I believe it should be mandatory that each state and country develop a plan for supporting families and treating children with Cerebral Palsy, based on quality. Cerebral Palsy is not a blanket diagnosis, meaning it does not affect each child and family the same way; therefore we need to treat each family and child as individuals in their diagnosis and understand the severity and other needs of the family before providing blanket interventions.

Teacher practices of self and others

The most valuable information that I gained from this review of literature is that family involvement is, in fact, critical in the progress of children with the diagnosis of Cerebral Palsy. As I mentioned in the introduction about the Early ACCESS program in Iowa, I serve children in a particular area from birth to three years old in their homes. Families of these children have an Individualized Family Service Plan, and the idea is to be family-friendly by doing services in the home environment. I need to examine my current outlook on family involvement and how I am involved with each family on my caseload. Not every child I work with has a diagnosis of Cerebral Palsy. In the cases where I do work with children that have the diagnosis, all service providers are involved with the family, including the speech pathologist, physical therapist, and occupational therapist. I believe it would be helpful to organize a meeting where the providers discuss the needs of the family, as well as meeting with the family to discuss what they need from us. For the two children I described in Chapter 1, each family of the child was involved at a different intensity level. It would be valuable and beneficial to sit with the parents and learn how we can best meet their needs. Even though we do home visits, we center on the child more than anything, and I would work to be involved with the family as a whole rather than the child as an individual. We do share ideas and activities with the family, but it appears that I do this more when families ask for this information. I believe it would be more beneficial to share activity ideas that could be done during daily routines so that each family member knows how to participate and interact with the child to make home intervention services family-friendly.

Frequency of interventions is going to be an on-going factor for me in recommendations of services to families. Time is a constraint for service providers and families involved with children with the Cerebral Palsy diagnosis. Throughout this review of research, studies described that some services were not available or accessible to families because of the time it takes for the providers to come into the home, or for the families to get to the location where services were being provided. I have set hours in which I work, and if time continues to be a constraint for families, I need to be more flexible in my availability to better meet the needs of the child. This review of research has shown me that families and service providers need to work together more often to provide for the child in need. Service providers in early intervention are to be a support to the child and the whole family. In order for this to occur, accessibility and availability of our services needs to be an important part of the delivery.

The three research questions that were reviewed in this study were:

1. What types of home interventions are used with children diagnosed with Cerebral Palsy?
    a. How frequent are home intervention services recommended for children with Cerebral Palsy?
2. What are the possible disadvantages of home intervention services for children with Cerebral Palsy?
3. What are the possible advantages of home intervention services for children with Cerebral Palsy?

This review was valuable for me because I work with children in special education between birth and three years old. I have little experience in working specifically with children diagnosed with Cerebral Palsy. At the time of doing this review, I was working with two children and their families, discussed in Chapter 1. I felt that by doing this review of research on this particular topic, I could learn and become more of an asset to the families in providing the proper frequency and services to them and for the families that might arise in the future. By doing this review, I learned that there are a lot of questions in the world of special education. It was also valuable to me to understand that I am not the only person with these specific questions and that the authors that have completed the studies mentioned throughout this paper are still left with questions as well. Continuing education in this field is beneficial to me in that I was able to learn more about the field of early intervention services and how it is handled around the world. I found it valuable to choose a topic in which I work daily and can connect the review of research that I have completed with the daily work I am doing with families and children in all aspects of special education.

References

Bartlett, D., & Palisano, R. (2000). A multivariate model of determinants of motor change for children with cerebral palsy. *Physical Therapy, 80*(6), 598-614.

Bonnier, C. (2008). Evaluation of early stimulation programs for enhancing brain development. *Foundation Acta Paediatrica, 97,* 853-858. doi: 10.1111/j.165-2227.2008.00834.x

Building the legacy: IDEA 2004. (2004, December). Retrieved from http://idea.ed.gov/

Cooley, C. (2004). Providing a primary care medical home for children and youth with cerebral palsy. *American Academy of Pediatrics, 114,* 1106-1113. doi: 10.1542/peds.2004-1409

Council on Children with Disabilities. (2007). Role of the medical home in family-centered early intervention services. *American Academy of Pediatrics, 120,* 1153-1158. doi: 10.1542/peds.2007-2638

Damiano, D. (2009). Rehabilitative therapies in cerebral palsy: The good, the not as good, and the possible. *J Child Neurol, 24*(9), 1200-1204. doi: 10.1177/0883073809337919

DeLuca S., Echols, K., Ramey, S., & Taub, E. (2003). Pediatric constraint-induced movement therapy for a young child with cerebral palsy: Two episodes of care. *Physical Therapy, 83*(11), 1003-1013.

Dictionary.com. (2011). Retrieved from http://dictionary.reference.com

Earlyaccessiowa. (2008). Retrieved from http://www.earlyaccessiowa.org/

Early ACCESS Procedures Manual. (2011). Retrieved from http://www.iowaidea.org/vnews/display.v/SEC/IFSP|Early%20ACCESS%20Procedure%20Manual

Gupta, S., & Bhargava, S. (2008). Play based stimulation program for infants with cerebral palsy and mental retardation. *Asia Pacific Disability Rehabilitation Journal, 19*(1), 114-121.

Harbourne, R., Willett, S., Kyvelidou, A., Deffeyes, J., & Stergiou, N. (2010). A comparison of interventions for children with cerebral palsy to improve sitting postural control: A clinical trial. *Physical Therapy, 90*(12), 1881-1897. doi: 10.2522/ptj.2010132

Hielkema, T., Hamer, E., Reinders-Messelink, H., Maathuis, C., Bos, A., Dirks, T., Doormaal, L.,Verheijden, J., Vlaskamp, C., Lindeman, E., & Hadders-Algra, M. (2010). Learn 2 Move 0-2 years: Effects of a new intervention program in infants at very high risk for cerebral palsy: A randomized controlled trial. *BioMed Central Pediatrics, 10*(76), 1-8.

Huang, I., Sugden, D., & Beveridge, S. (2008). Assistive devices and cerebral palsy: Factors influencing the use of assistive devices at home by children with cerebral palsy. *Child Care, Health, and Development, 35*(1), 130-139.

Ketelaar, M., Vermeer, A., Helders, P., & Hart, H. (2000). Parental participation in intervention programs for children with cerebral palsy. *Topics in Early Childhood Special Education, 18*(2), 108-120.

Larroque, B., Ancel, P., Marret, S., Marchand, L., Andre, M., Arnaud, C., Pierrat, V., Roze, J., Messer, J., Thiriez, G., Burguet, A., Picaud, J., Breart., G., & Kaminski, M. (2008). Neurodevelopmental disabilities and special care of 5-year-old children born before 33 weeks of gestation (the epipage study): A longitudinal cohort study. *The Lancet, 371*, 813-820.

McConachie, H., Huq, S., Munir, S., Akhter, N., Ferdous, S., & Khan, N. (2001). Difficulties for mothers in using early intervention services for children with cerebral palsy in Bangladesh. *Childcare, Health, and Development, 27*(1), 1-12.

Nordmark, E., Hagglund, G., Pedersen, H., Wagner, P., & Westbom, L. (2009). Development of lower limb range of motion from early childhood to adolescence in cerebral palsy: A population-based study. *BMC Medicine, 7*(65), 1741-1750. Doi: 10.1186/1741-7015-7-65

Novak, I., & Cusick, A. (2006). Home programmes in paediatric occupational therapy for children with cerebral palsy: Where to start? *Australian Association of Occupational Therapists, 53*, 251-264. doi 10.1111/j.1440-1630.2006.00577.x

Orton, J., Spittle, A., Doyle, L., Anderson, P., & Boyd, R. (2009). Do early intervention programmes improve cognitive and motor outcomes for preterm infants after discharge? A systematic review. *Developmental Medicine & Child Neurology, 51*, 851-859. doi: 10.1111/j.1469-8749.2009.03414.x

Parents as teachers: Vision/mission history. (2010). Retrieved from http://www.parentsasteachers.org/about/what-we-do/visionmission-history

Parents as teachers: Results. (2010). Retrieved from http://www.parentsasteachers.org/results

Sugden, D., & Beveridge, S. (2008). Assistive devices and cerebral palsy: Factors influencing the use of assistive devices at home by children with cerebral palsy. *Childcare, Health, and Development, 35*(1), 130-139. doi: 10:1111/j.1365-2214.2008.00898.x

Tsorlakis, N., Evaggelinou, C., Grouios, G., & Tsorbatzoudis, C. (2004). Effect of intensive neurodevelopmental treatment in gross motor function of children with cerebral palsy. *Developmental Medicine & Child Neurology, 46*, 740-745. doi 10:1017/S0012162204001276

Understanding cerebral palsy -- the basics. (2005-2011). Retrieved from http://www.webmd.com/brain/understanding-cerebral-palsy-basic-information

Woodward, L., Anderson, P., Austin, N., Howard, K., & Inder T. (2006). Neonatal MRI to predict neurodevelopmental outcomes in preterm infants. *The New England Journal of Medicine, 355*(7), 685-694.