Parental Struggles with Obtaining Services for Children with Special Needs

Regina Lynn Carr

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PARENTAL STRUGGLES WITH OBTAINING SERVICES FOR CHILDREN WITH SPECIAL NEEDS

by

Regina Lynn Carr

A Thesis
Submitted to the Graduate School of The University of Southern Mississippi in Partial Fulfillment of the Requirements for the Degree of Master of Science

Approved:

Dean of the Graduate School

May 2011
ABSTRACT

PARENTAL STRUGGLES WITH OBTAINING SERVICES FOR
CHILDREN WITH SPECIAL NEEDS

by Regina Lynn Carr

May 2011

This thesis is an in-depth review of the literature addressing parental struggles, attitudes, and perceptions of barriers in obtaining services for young children with special needs. Researchers, policy makers, and educators need to be aware of how families identify and report their experiences with obtaining services for their young children. Service providers for young children and families with special needs must understand the perspective of the family in order to better serve the children and families. Implementations for future research, practice, and policy changes are discussed.
ACKNOWLEDGMENTS

The writer would like to thank the thesis chair, Dr. Chuck West, and the other committee members, Dr. Hollie Filce and Dr. Sheila Brookes, for their advice and support throughout the duration of this project. I would especially like to thank Dr. Sheila Brookes for her enormous patience and for encouraging me when I thought I was not going to make it through.
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CHAPTER I

INTRODUCTION

Children with special needs require services and care to optimize their development and growth. This paper summarizes the research literature regarding parental perspectives of barriers to obtaining services for young children with special needs (children ages birth to five). Policy makers, educators, family and child service professionals, and service providers need to be aware of the barriers parents perceive when attempting to obtain services for their child with special needs. For purposes of this paper, a child with special needs is defined as a child who has a cognitive, social, or sometimes physical limitation (Westling & Fox, 2000).

It was the beginning of the fall semester of 2009. As an early intervention master's student, I was so excited to begin my work with children needing early intervention services. My first assignment for class was to identify a child with a speech/language delay. There was a little boy, 31 months old, named Eric in a local early care and education program that had a speech/language delay. He had receptive language, communicated greatly using gestures, but had limited-to-no expressive language.

I was excited about working with Eric. He had a beautiful smile and he would always smile even bigger when I came into his class. Eric also displayed some behavioral issues most likely because of his frustration in communicating with other children and teachers due to his speech/language delay. At times, his behavior was hurtful to not only himself, but to his classmates and the classroom property. As the semester progressed, I began asking questions about his delay and the services he was...
receiving. His classroom teacher said he had only been in the program a few months and had not yet been assessed in this community. The program knew he had a speech/language delay because his mother reported that he had been assessed before she moved to this community. Unfortunately, the agencies did not work well together and the prior agency would not transfer the child’s assessment, therefore, the child had to be assessed again.

Because Eric was 31 months old, he fell under the umbrella of early intervention services. Early intervention is defined as services provided to children with an identifiable disability or have conditions known to cause delays. His classroom teacher allowed me to take the lead in helping to obtain services, or at the very least screening, Eric. After talking with the program director and the mother, proceedings began. When the mother called for early intervention services, she was told that the child would soon be 36 months and would be take care of by the school system. So his mother did not want to push the issue with early intervention services and was going to patiently wait until the child turned 36 months to be assessed by the school district. However, I encouraged Eric’s mother to demand screening and get a possible diagnosis, so he could begin services sooner.

Eric was assessed at 33 months and diagnosed as being delayed in speech and cognition. He received a few services from early intervention services before the winter break. When returning to school in January, Eric would turn 36 months and early intervention services would stop and the school would pick up services. It was several weeks into the spring semester and Eric had not received services from the school district. After some inquiry, Eric’s mother told his teacher that she lived in one county
and Eric’s early care and education program was in another county and neither school
district was claiming responsibility for providing services. Sometime in March 2010, the
two districts were able to collaborate one of the two school districts began providing
services.

The following fall, I was this Eric’s preschool teacher. Delighted to have him in
my class, I was eager to work with his mother and his school district service provider.
One day per week, for approximately 30 minutes, Eric was pulled out of preschool class
to receive services. I asked the early interventionist, from the school district, what I
could do in the classroom to help Eric be successful in his classroom and her statement
shocked me. She told me she did not know how I could help him in the classroom
because she did not know what was wrong with him. I asked her about the services he
was receiving, what she was doing during their weekly visits, and how I could duplicate
those activities in my classroom on a daily basis. Again, her comment shocked me as I
was informed she was using flashcards with him. She reported that she would show him
two picture cards and have him tell her which of the two pictures barked, mooed, etc.
This experience, as a teacher, began my journey to find out what struggles and barriers
parents faced when trying to obtain services for their children with special needs. Was
this an isolated case or are there other children out there like him?

An exhaustive search of the literature was conducted for this review. The subject
area used in the search was early intervention. The databases used were: (a) Academic
Search Premier, (b) Dissertation and Thesis (Proquest), (c) EBSCOhost Electronic
Journal Services (EJS), (d) ERIC, (e) JSTOR, (f) Professional Development Collection,
and (g) PsycINFO (on EBSCO). The key word search for this literature review was: (a)
early intervention; (b) special education; (c) parental perceptions; and (d) service barriers. These key words produced no literature related to parental perceptions about barriers when attempting to obtain services for their child with special needs.

Therefore, the word search criteria was expanded and is as follows: (a) parental perceptions with obtaining services for children with special needs; (b) parental struggles with obtaining services for children with special needs; (c) parental perceptions with obtaining early intervention services; (d) parental struggles with obtaining special education services; (e) services for children with special needs; and (f) early intervention services for young children. To keep this literature review current, journal articles from the year 2000 through the year 2011 were reviewed. The search uncovered three articles related to special health care needs, five articles related to developmental delays, one article related to special education services, and four articles related to early intervention services. There is a vast amount of literature focusing on parental perceptions in general. However, very little focuses on their views on obtaining services. For the purpose of this paper, the term special education is defined as modified and adaptive instruction that differs from modifications and adaptations of typical students (Howard, Williams, & Lepper, 2005).
CHAPTER II
HISTORY OF EARLY INTERVENTION

The foundation for the field of early intervention was laid in the late 1800's with the establishment of early childhood programs for typically developing children. These early childhood programs followed the philosophies of German educator, Friedrich Froebel (1782-1852). Frobel brought to light the importance of child-centered learning and the importance of children’s play when he formed his first kindergarten in 1836 (Gordon & Browne, 2004). The works of Italian physician and educator, Maria Montessori (1870-1952), are especially significant to the field of education of children with special needs because Montessori believed that children should learn in “graded sequences, [with] self-paced and self-correcting instructional materials, and learning through the sensory modalities through active involvement with the environment” (Hanson & Lynch, 1995, p. 4).

One of the first publications in the field of early intervention was in 1939 when H. M. Skeels and H. B. Dye placed two “helpless” babies from an orphanage in the care of mentally impaired adult women who resided in an institution. The babies’ intelligence quotients (IQ) rose by 40 points after being in the care of the women for only six months. After a few more months in the care of the women, the babies’ IQs rose to the mid-90s. Skeels and Dye convinced authorities to place 13 more children in the care of teen-age mentally challenged girls who lived in institutions (Howard et al., 2005). Skeels and Dye followed these children, who had been removed from orphanages and placed in care of the teenage girls, for 25 years. They found that most all of the children had “completed high school, married, and had normal children” (Howard et al., 2005, p. 80).
Other historical factors that led to establishing the field of early intervention includes the historical Supreme Court case of Brown v. the Board of Education in 1954. This monumental desegregation case focused on guaranteeing that all children had a right to a descent public education. Consequently, Brown v. the Board of Education brought to light that black children were entering school disadvantaged, cognitively and educationally, compared to their white cohorts (U. S. Supreme Court, 1954).

*Life* magazine, in 1959, ran portraits of life in the Appalachian Mountains depicting the cognitive and social delays of poor white families in West Virginia and through the southern Appalachian chain. The works of early experience theorists, Donald Hebb (1949), J. McVicker Hunt (1961), and Harry Harlow (1958) paved the way for a group of experimental and clinical psychologists, grounded in learning theory, to explore the consequences of early experiences based on poor Appalachian families. Earlier works of Skeels and Dye (1939), along with works of Hebb (1949), Hunt (1961), and Harlow (1958) laid the cornerstone for Head Start (Ramey & Ramey, 1998).

In the 1960s, Head Start, as part of President Johnson's War on Poverty, had as its mission to reach children who were economically disadvantaged in the U. S. (Hanson & Lynch, 1995). The main focus of Head Start was to ensure that economically disadvantaged children were developmentally ready to enter elementary school. The first Head Start program was a summer program designed to help three- and four-year-old children be ready for school (Head Start History: 1965 to Present, 2011). A study conducted by Westinghouse 1969 found there was not a lasting impact of the summer program, so full-year programs were put into place (Westinghouse Learning Corporation and Ohio University, 1969). The full year programs were found to be more effective.
From the Westinghouse study three themes emerged that had an impact on early intervention. First, interventions must begin earlier and last longer. Second, interventions should not stop when children enter school. And third, support to families should be a component of intervention (Westinghouse Learning Corporation and Ohio University, 1969).

Designed as an intervention program, Head Start is unique because the program is “community based, stressed parent involvement, and required a comprehensive approach with the participation of different types of professionals” (Hanson & Lynch, 1995, p. 5). The Head Start model of collaborative partnership with families influenced the growth of other family-oriented approaches in meeting the needs of economically disadvantaged children. Head Start programs are required to serve children with disabilities; specifically, programs must set aside ten percent of their enrollment for children with disabilities (History of Head Start: 1965 to Present, 2011).

Several legal cases from the 1970s paved the way for protection of children with special needs to have access to “free and fair public education” (Hanson & Lynch, 1995, p. 5). The Pennsylvania Association for Retarded Children (PRAC) v. Commonwealth of Pennsylvania (1971) brought attention to the educational rights of children with disabilities and the need for protection under the law. These cases led to an important piece of significant legislation in 1975, the Education for All Handicapped Children Act, P.L. 94-142.

Hanson and Lynch (1995) describe P.L. 94-142 as:

six major principles: a zero reject model entitling children to a free appropriate education; nondiscriminatory testing, classification, and placement; an
appropriate and individualized education; education in the least restrictive appropriate placement; procedural due process; and parent participation and shared decision making. (p. 5)

This law did not apply to children under the age of three. However, some states provided services to this group of children and these services played a critical role in establishing early intervention services (Hanson & Lynch, 1995). Other public laws such as “Handicapped Children’s Early Education Assistance Act (HCEEA) (P.L. 90-538) (1968) and the 1972 Economic Opportunity Amendments (P.L. 92-424)” (Hanson & Lynch, 1995, p. 5) were enacted to increase services for children with disabilities, especially those needing early intervention services. Based on those public laws that were created to provide increased services to children with special needs, the 1972 Economic Opportunity Amendments “mandated that Head Start services be provided to children with disabilities from low income families” (Hanson & Lynch, 1995, pp. 5-6).

In 1975, Congress approved a law that required free and appropriate education of all children in the least restrictive environment. The original legislation is Education of All Handicapped Children Act (EAHCA) and today is referred to as the Individuals with Disabilities Education Act (IDEA). “Prior to IDEA’s passage, one million children were excluded from public education because of their disabilities” (Howard et al., 2005, p. 11). In 1990, the Education of All Handicapped Children Act (EHA) was amended to IDEA and in 2004 it was reauthorized. Table 1 describes recent landmarks in early intervention services.
Table 1

*Recent Landmarks in Early Intervention Services*

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<th>Date</th>
<th>Landmark Description</th>
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<tr>
<td>1. 1965</td>
<td>Project Head Start was established to serve 3–and 4-year-olds living in poverty</td>
</tr>
<tr>
<td>2. 1968</td>
<td>Handicapped Children’s Early Education Program established to fund model preschool programs for children with disabilities</td>
</tr>
<tr>
<td>3. 1972</td>
<td>Economic Opportunity Act required Head Start to reserve 10% of its enrollment for children with disabilities</td>
</tr>
<tr>
<td>4. 1975</td>
<td>P.L. 94-142, The Education for All Handicapped Children Act, provided incentive funding for programs serving preschoolers with disabilities ages 3 to 5 years</td>
</tr>
<tr>
<td>5. 1986</td>
<td>P.L. 99-457 amends P.L. 94-142 to require services to children ages 3 to 5 with disabilities and to provide incentives for programs serving infants and toddlers with are developmentally delayed or at risk of developmental delay</td>
</tr>
<tr>
<td>6. 1990</td>
<td>Head Start Expansion and Quality Improvement Act reauthorized and expanded Head Start program through 1994</td>
</tr>
<tr>
<td>7. 1997</td>
<td>P.L. 105-17, the 1997 amendments to IDEA, renew early intervention efforts; mandates schools report progress to parents of children with disabilities as frequently as they report to parents of non-disabled children; articulated a new challenge to improve results for these children and their families</td>
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These laws and mandates, enacted to protect and provide services to children with special needs, have influenced the early intervention programs for children and families today. These services to children with disabilities have been a strong partnership of communities, families, and professionals’ partnership that has evolved into the multidisciplinary and transdisciplinary approach of today (Ongam, 2001).
CHAPTER III
ECOLOGICAL FRAMEWORK

An important theory that can be applied to our understanding of parental attitudes towards obtaining services for their children with special needs is Urie Bronfenbrenner’s ecological model (Figure 1). Bronfenbrenner saw the family as a system that functions inside a box surrounded by other components that directly and indirectly interact with the family (Bronfenbrenner, 1986). How the family members function with other members and the daily interactions with other entities such as the neighborhood, school and work are called the microsystem (Bronfenbrenner, 1986). The microsystem is important to all families, but especially important to parents of children with special needs because the support system around the family can help and or hinder the family when seeking services for their children.

Applequist (2009), Nolan, Orlando, and Liptak (2007), and Hendrickson, Baldwin, and Allred (2000) reported parental difficulties obtaining services in their communities, having access to services, or even being aware of services provided. According to Bronfenbrenner’s (1986) ecological model, these services to families’ fall into the exosystem. There are three components of the ecosystem that affect child development through the family process. These components are the “parents’ workplace, the parents social networks, and community influences on the family function” (Bronfenbrenner, 1986, p. 728).

Other factors that families face, according to the ecological model, are the neighborhood and community where the family resides. This is part of a family’s mesosystem system. The makeup of the community such as location, facilities, and safety are not the only components of the mesosystem that impact the family. The
attitudes of the community/neighborhood are also vital, especially to families of children with special needs. Families need the support of their community/neighborhoods as the child with special needs becomes a working part of the community/neighborhood (Bronfenbrenner, 1986).

The final two components of the ecological model that affect parents of children with special needs is the macrosystem, which includes the laws, culture, and norms of society, and finally the chronosystem, which relates to time (Bronfenbrenner, 1986). The history of special education, changes in laws regarding people with special needs, and changes in norms of society in providing services to this population directly impact how families obtain and use services provided and makes the ecological theory model vital to families of children with special needs.
Figure 1. Ecological Framework. In the center of the Ecological Framework is the child surrounded by the microsystem that includes the family. The next system affecting the outcome of the child is the mesosystem that includes the child’s immediate community. The Exosystem is the next system that includes the institutional community. The Macrosystem that includes political and social perspectives is the final layer of the Ecological framework. The remaining component of the Ecological Framework is the chronosystem or time. Adapted from: Saskatchewan Learning (2011). Nature vs. nurture. Retrieved from www.sasklearning.gov.sk.ca/branches/psych_portal/module_1m1t1.2.shtml
CHAPTER IV
PAST AND PRESENT MODELS

It is important to understand the history of the field of early intervention that has lead to the present day models and services to children with special needs. It is also important to understand the societal perspective of early intervention. Early Christians believed that people with mental illness were unholy and unable to communicate with God (Alper, 2003). Through the spread of Christianity many Christians were humane to persons with mental illness. Alper (2003) states these early Christians believed the old Yiddish proverb that said “a complete fool is half a prophet” (p. 5). However, others did not have the same beliefs as the early Christians. Calvin and Martin Luther had a different view of people with mental illness. They considered persons with mental illness as persons possessed by Satan. These people were also “considered to be witches and burned at the stake by Puritans” (Alper, 2003, p. 5).

Persons with mental illness, and those seen as not normal, were placed in institutions to be with others like themselves. Many families did not have a choice and had to institutionalize their loved ones. Residents in these institutions were tied to chairs, locked in rooms, or roamed around with little or no supervision (Alper, 2003). Dr. Burton Blatt (1987), a special educator and advocate for human rights for persons with mental illness and photographer Fred Kaplan brought to light what was happening in institutions. A series of articles and photographs were published in Christmas in Purgatory in 1966 and revealed the abuse and neglect occurring in these institutions (Alper, 2003). Eventually these articles were published in Look magazine. Burton Blatt, in his effort to fight for the rights of those with mental illness, said
There is shame in America. Countless human beings are suffering needlessly. They are the unfortunate victims of society's irresponsibility. Still others are in anguish, for they know or suspect the truth. Wittingly, or unwittingly, they have been forced to institutionalize their loved ones into a life of degradation and horror. (p. 19)

The shocking reports published about the inhumane treatment of some persons with mental illness caused a stir among advocates. Human rights advocates and parents stood together to put an end to inhumane treatment of people in institutions. These advocates filed class-action law suits designed to end the horrendous conditions in institutions. Furthermore, increasing demands were placed on state agencies to transform institutions into family-like group homes including educational, vocational, and recreational opportunities for residents. Federal funding and support was made available during the 1960s with the influence of the Kennedy family (Alper, 2003).

Services for persons with disabilities have come a long way since the early days of institutions. Today, regional centers still provide some services to persons with disabilities; most of these facilities are community-based (Lakin, Prouty, Polister, & Coucouveranis, 2003). In 1975, Public Law 94-142, the Education of All Handicapped Children Act (EHA) stated all children had the right to free and appropriate education (FAPE), which included children with severe disabilities (Alper, 2003). In 1997, Public Law 105-17, IDEA was amended to include the definition of mental retardation as defined by the American Association of Mental Retardation (AAMR). Services for "infants, toddlers, and youth with severe disabilities, such as participation in state- and district-wide assessments, alternate assessments, positive behavioral supports, access to
inclusive settings and the general education curriculum, and vocational services” (Alper, 2003, p. 3) were also mandated. These are often referred to as “Part C” services, as they are currently included in Part C of IDEA.

For children younger than school age, services are provided by state agencies through an early intervention program. While IDEA, discussed earlier, gives states the authority to designate the lead agency for early intervention services most early intervention programs are organized and operated mainly through the state’s department of health (The National Early Childhood Technical Assistance Center, 2001). Currently, best practices for providing services to young children is through a multidisciplinary or transdisciplinary approach and in the least restrictive and most natural environment, which includes inclusion in programs with typically developing children that is family and community centered (Ongam, 2001). Through a multidisciplinary approach, service providers, family members, and other significant child care providers are part of a team that delivers services to the child in his/her natural setting (i.e., in the home or child care setting). In addition to the multidisciplinary team, a transdisciplinary team can also provide services to the child. The transdisciplinary team is different from the multidisciplinary team in that within the transdisciplinary team there is role release, in that each team member is trained by the others so that they can implement services collaboratively (Linder, 2008). The transdisciplinary approach can be used with children with all sorts of delays or diagnoses. The transdisciplinary, play-based assessment is a tool that allows professionals to observe children in a clinical setting with a play therapist, in the classroom setting (school or early care and education setting) and in the home. The team compiles all the data from observations and determines the services that
need to be provided and provides these services in the child’s natural setting (Linder, 2008).
CHAPTER V

REVIEW OF THE LITERATURE

Historically speaking, services to persons with special needs have become more humane with the goal of the person becoming a more functional member of society. While this is a step in the right direction, this literature review will explore the process of obtaining services through the lens of parents of children with special needs who are seeking out services for their young children.

This section will discuss what the literature indicates about services provided to persons with developmental delays, special health care needs, and children receiving special education services and parental perspectives and experiences obtaining services for their child.

Figure 1. Subject Area Literature Review. Journal articles reviewed are listed according to subject area. Three articles specifically relating to special health care needs were reviewed as indicated by the grey color. Five articles focusing on developmental delays were reviewed indicated by the blue color. One article related to special education services indicated by the red color. Four articles related to early intervention were reviewed indicated by the green color.
Developmental Delays

The definition of developmental delay and being diagnosed as developmentally delayed differs from state to state. Eligibility criteria for early intervention services varied state by state (The National Early Childhood Technical Assistance Center, 2001). It is important to understand that each state has different qualifying criteria for early intervention services. As families may be required to move from one state to another, a child receiving services in one state may not qualify for the same services, or any services, in another state. Table three compares nine different state’s criteria for qualifying for early intervention services. States were chosen based on region.

Table 2

State Criteria for Early Intervention Services

<table>
<thead>
<tr>
<th>State</th>
<th>Criteria</th>
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| 1. Alaska | A child under the age of three and:  
(1) Experiencing developmental delay or disability; or  
(2) At risk of experiencing developmental delay or disability if early intervention services are not provided  
Source: www.touchngo.com/lglnctr/akstats/Statutes/Title47/Chapter20/Section080.htm |
| 2. California | Infants and toddlers birth to 36 months if:  
(1) There is a developmental delay in physical, cognitive, communication, social or emotional, or adaptive including vision and hearing and are under 24 months of age at time of referral;  
(2) There is a 33% delay in one or more areas of development over the age of 24 months; or  
(3) There is a 50% delay in one or more areas of development; or  
(4) There is a 33% delay in two or more areas of development; or  
(5) There is an established risk condition of known etiology (cause) with a high probability of resulting in delayed development  
Source: http://www.dds.ca.gov/EarlyStart/WhatsES.cfm#1 |
Table 2 (continued).

<table>
<thead>
<tr>
<th>State</th>
<th>Criteria</th>
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<tr>
<td>3. Colorado</td>
<td>An infant or toddler who: (1) Has a 25% or greater delay in one or more areas of development when compared with chronological age; or (2) The equivalence of 1.5 standard deviation or more below the mean in one or more areas of development Source: <a href="http://www.eicolorado.org/index.cfm?fuseaction=Policies.content&amp;linkid=637">http://www.eicolorado.org/index.cfm?fuseaction=Policies.content&amp;linkid=637</a></td>
</tr>
<tr>
<td>4. Hawaii</td>
<td>A child must be: (1) Developmentally delayed in one or more of the five areas of development (physical, cognitive, communication, social or emotional, or adaptive) and/or: (2) Biologically at-risk (a diagnosed physical or mental condition that has a high probability of resulting in developmental delay if early intervention serves are not provided Source: <a href="http://www.hi5deposit.com/health/family-child-health/family-child-health/eis/eligibility.html">http://www.hi5deposit.com/health/family-child-health/family-child-health/eis/eligibility.html</a></td>
</tr>
<tr>
<td>5. Massachusetts</td>
<td>A child must be: (1) Diagnosed with a neurological, metabolic, or genetic disorder, chromosomal anomaly, medical or disabling condition; (2) Exhibits a 25% in one or more areas of development (physical, cognitive, communication, social or emotional, or adaptive); (3) At least one standard deviation below the norm; (4) Questioned quality of developmental skills based on the informed clinical opinion of a multidisciplinary team; (5) Risk of developmental delays or disorders Source: <a href="http://eiplp.org/documnets/standards3.pdf">http://eiplp.org/documnets/standards3.pdf</a></td>
</tr>
<tr>
<td>State</td>
<td>Criteria</td>
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| 6. Mississippi | A child birth through two who are:  
(1) Experiencing a developmental delay of 1.5 standard deviation below the mean or a 25% delay in one or more areas of development (physical, cognitive, communication, social or emotional, or adaptive);  
(2) Diagnosed with a physical or mental condition that has a high probability of resulting in developmental delay; or  
(3) Diagnosed with a medical condition that has a high probability of causing substantial delays if early intervention services are not provided. | http://www.dmh.state.ms.us/ ei_services_requirements.htm |
| 7. New York      | To be eligible for services, children must be under 3 years of age and have a confirmed disability or established developmental delay, as defined by the State, in one or more of the following areas of development: physical, cognitive, communication, social-emotional and/or adaptive. | http://www.health.state.ny.us/community/infants_children/early_intervention/ |
| 8. Oklahoma     | Service eligibility requirements:  
Infants and toddlers birth through 36 months of age who: exhibit a delay in their developmental age compared to their chronological age of 50% in one, or 25% in two or more of the following areas: cognitive, physical, communication, social/emotional, or adaptive development; or  
have a diagnosed physical or mental condition that has a high probability of resulting in delay. This includes, but is not limited to: chromosomal disorders, neurological abnormalities, inborn errors of metabolism, genetic disorders, congenital malformations of the brain, congenital infections, sensory abnormalities, impairments, or identified syndromes. | http://www.ok.gov/abletech/documents/SoonerStart.pdf |
Table 2 (continued).

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<th>State</th>
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<td>9. Wisconsin</td>
<td>Children ages birth to 36 months: Eligibility is based on a diagnosed disability or significant delay in one or more areas of development. The team will evaluate the child’s ability to: learn (cognitive development); move, see and hear (physical/motor development); communicate and understand other’s communication (speech and language development); respond to and relate with others (social and emotional development); and eat, dress and care for daily living needs (adaptive development). A Birth to 3 service coordinator helps the family understand and participate in the evaluation process. Source: <a href="http://www.dhs.wisconsin.gov/bdds/b3broch/general.htm">http://www.dhs.wisconsin.gov/bdds/b3broch/general.htm</a></td>
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Five different studies focused specifically on obtaining services for developmental delays revealed several themes (Hendrickson, Baldwin, & Allred, 2000; Lyons, O’Malley, O’Connor, & Monaghan, 2010; Paradice Wood, Davies, & Solomon, 2007; Raspa et al., 2010; Rosenberg, Robinson, & Fryer, 2002). Hendrickson et al. (2000), Lyons et al. (2010), Paradice et al. (2007), Raspa et al. (2010), and Rosenberg et al. (2002) conducted parental interviews using questionnaires; one study followed the children and families for a period of six months and contained data on pre- and post-services. While Lyons et al. (2010) conducted pre- and post-service focus groups. Rosenberg et al. (2002) used pre- and post-service questionnaires. A positive reoccurring theme from parents of children with developmental delays is that parents felt very confident in their ability to obtain services for their child and felt confident in helping their child to develop and learn (2010 Paradice et al., 2007; Raspa et al.).
Obtaining Services

Parents also felt confident in knowing how to obtain services for their children in spite of the child’s disability Paradice et al., 2007; (Raspa et al., 2010). Prior to intervention, Paradice et al. (2007) found a more collaborative effort between classroom teachers, services providers, and parents, with 54% of the parents reporting they felt confident that their child was receiving services. After implementation of intervention, 31% of the parents reported being very confident in the services their child was receiving because of a more collaborative effort.

Working with Pediatricians

In addition, Hendrickson et al. (2000) found that parents felt frustrated when reporting concerns for their child’s development to the pediatrician. Parents felt their concerns were not addressed. Parents also indicated they were given generic responses such as “he will grow out of it” or “she will catch up with others.” Parents reported they did not feel the pediatrician took their concerns seriously when parents mentioned their concerns about their child’s development. Furthermore, Hendrickson et al. (2000) found that parent confidence in pediatricians was greatly diminished if the parent had an older child with special needs. Raspa et al. (2010) found that parents felt disconnected from the service provider, did not know who to call when the family needed help, and did not have anyone to talk to about their situation.

Lyon et al. (2010), in a separate study, examined parental expectations and experience (pre- and post-group) with an intervention service. Pre-group findings indicated that parents were confident that the children would gain significant communication skills and parents would know how to help their child. Additionally, the
parents were confident that clinicians would make their child comfortable in the group. Post-group findings indicated that the majority of parents were satisfied with the progress their children made and parents felt they learned how to better facilitate their child’s development (Lyons et al., 2010). A few parents reported their expectations were not met (Lyons et al., 2010). These parents expected more progress for their child than was achieved at the conclusion of the study. These studies concluded that parents’ confidence level in obtaining services was higher post-study than pre-study (Hendrickson et al., 2000; Lyons et al., 2010; Paradice et al., 2007; Raspa et al., 2010; Rosenberg et al., 2002). Some children with disabilities are diagnosed with special health care needs and mental health needs.

Special Health Care Needs

When examining the effects of poverty on parents’ ability to obtain services for their children with special needs, Porterfield & McBride (2007) found that three-fourths of children diagnosed with special health care needs actually received those services. Additionally, parents whose income fell below the Federal Poverty Rate were less likely to recognize that their child needed special services and were less likely to obtain these services compared to those parents whose income was above the poverty rate. Porterfield & McBride (2007) found that parental education level had less impact on access to services than did income level; mothers who had not completed high school “were about 13 percentage points less likely to indicate their child needed special physician services compared with mothers who had college degrees” (p. 327). Additionally, having health insurance was a key factor in seeking services (Porterfield & McBride, 2007). Parents also indicated that having inadequate health insurance coverage for therapy services was
a barrier to obtaining services for their child with special needs; additionally parents
indicated another barrier was a “lack of resources at school” (p. 327).

A study conducted by Nolan, Orlando, & Liptak, (2007) examined whether or not
services provided to children with special health care needs is truly family-centered. This
study consisted of 132 literate, English speaking parents of children with special health
care needs. Information was obtained using a survey that took parents about 15 – 20
minutes to complete. In all, 83 families completed the survey (Nolan et al., 2007).
Parents indicated that 84% of the children were diagnosed with a disability at birth. Most
parents reported they did not have difficulties obtaining acute care or therapy services,
especially when they received assistance from the medical provider, however, 46%
reported having difficulties obtaining medical equipment (Nolan et al., 2007). Parents
indicated struggles with communication between the medical personnel and school. Half
of the parents stated medical personnel never or rarely communicated with their child’s
school and 27% of parents reported that medical personnel never or rarely involved
families in the decision making process. Thirty-eight percent of parents also indicated
that they were never or only rarely informed of service providers in their community and
22 % indicated they were never or only rarely informed about community based
programs/services (Nolan et al., 2007). Parents (88%) reported receiving help from
professionals to obtain special therapy services and 86% reported being referred by
professionals and had no problems obtaining those services (Nolan et al., 2007).
Research of Nolan et al. (2007) reiterate research findings of Hendrickson et al. (2000)
indicating that parents feel medical service providers do not listen to them and parents are
not included in the decision making process.
Children with special needs are not limited to receiving services through the school system. Some children diagnosed with special needs include special health care needs and mental health care needs. Children with special health care needs often need services provided through the medical community and may include mental health services. A study in Vermont in 2005 indicated that 5% of children and adolescents in the state received some type of public mental health service (Padiani, Banks, Simon, Van Vleck, & Pomeroy, 2005). To determine the number of children receiving mental health services the researchers used the “access ratio calculated by dividing community health utilization rate for each special population by community mental health utilization rate for the general population as a whole” (p. 433). Researchers also obtained data from local service providers to the state mental health authority based on electronic reporting to the state agency (Padiani et al., 2005). The information obtained through the electronic reporting to state agencies contained demographic information such as gender, age, and birth date (Padiani et al., 2005).

Special Education Services

Since the original passage of Public Law 94-142 in 1975, children with special needs are guaranteed free and appropriate education. Applequist (2009) examined parental perspectives of special education. Howard et al. (2005) define special education as “specifically designed instruction that includes adaptations that are significantly different from modifications normally made for typical students and are necessary to offset or reduce the adverse effects of the child’s disability” (p. 532). Applequist (2009) surveyed 32 parents and grandparents of children ages one year to 18 years receiving special education services; these families were from rural and urban areas. Families also
had diverse ethnic backgrounds. The results indicated that families living in rural areas have more difficulty obtaining referrals for children mainly because they were not fully informed about services available (Applequist, 2009). Additionally, parents described a multitude of feelings when entering the program. Some feelings indicated were those of isolation, inadequacy, hunger for information and guidance, and being overwhelmed. Parents also indicated a “sense of confusion regarding the system of services” (Applequist, 2009, p. 9); some struggled to become informed about their child’s needs and services available because the information received was incomplete or confusing.

Applequist (2009) corroborated the findings of Hendrickson et al. (2000) in that parents felt the physician was not aware of early intervention services or parents were not referred to early intervention services. Some parents indicated they searched for a physician who understood children with special needs (Applequist, 2009). Prior to participating in the research project some parents were not aware of early intervention services available to their child. Those who were in early intervention programs felt professionals helped parents better understand their child’s needs and were satisfied with the services they received (Applequist, 2009). The research findings of Applequist (2009) substantiates the research findings of Nolan et al. (2007) and Hendrickson et al. (2000) in that medical personnel did not listen to parental concerns.

Services for Children with Special Needs

Services for children with special needs can be provided either in the home or in the classroom, public school or early care and education setting. This section reviews the literature of professionals delivering services in the home and in the classroom.
Professionals in the Home

The research on professionals providing early intervention services in the home is limited and is an area that needs more exploration in order for service providers and families to better understand the effects of intervention services to children and families. Only one article was obtained that specifically reviewed the role of professionals in the home. Talay-Ongan (2001) conducted a study focusing on the importance of the role early intervention service providers’ play.

Early intervention practices have shifted from child-centered to family-centered practices in which the family is a part of the team (Talay-Ongan, 2001). These services are community-based and research indicates the earlier the intervention services are provided, the more lasting the results will be (Talay-Ongan, 2001). The work of Dunst and his colleagues has been a pioneering influence in how service providers interact with families. Dunst et al. (1998) introduced two important terms that are guiding forces in family-centered care. The terms of Dunst et al. are enabling families, which “implies creating means and opportunities for families to apply their present abilities and competences” (p. 224). The term empowering families, which “implies interacting with them in ways which allow the families the maintenance or acquisition of control over their own lives” (Talay-Ongan, 2001, p. 224).

Families are seen as being able to make decisions regarding what is best for their child and what the individual family needs. These practices focus on the capabilities and the existing social support of families as a way of optimizing the intervention and development of the child with special needs. This practice also recognizes that the family is the one constant in the child’s life and services revolving around that constant are
important to the child as the service providers are variable. These professionals are partners with the family (Talay-Ongan, 2001).

**Professionals in the Natural Environment**

Children with disabilities receive services under the Individuals with Disabilities Education Act of 1997 (Part B and C of IDEA) to receive services in their natural environment. For many young children this natural environment is an early care and education program. This may include children in family child care settings with an individual family child care provider. Children in family child care are protected by IDEA and should receive services in their natural environment, whether that be in an early education setting, their home, or in the family child care provider’s home.

Many family child care providers are not formally educated in the area of child development and have gained their knowledge based on their own personal experiences as a parent or caregiver. These family care providers are the sole child care provider for the child and may recognize nuances that develop over time (Freeman & Vakil, 2004). Although different in approaches to providing child care, family care providers and the early care and education teacher play similar roles when it comes to being part of the team for a child with special needs. Family care providers are expected to be part of the Individualized Family Service Plan (IFSP) Team when planning services for children with special needs as well as being the one who implements those activities and interventions into the early childhood program for the child. An IFSP is a road map of intervention services for children with disabilities and their families. The major difference between family care providers and early care and education providers is that the family care provider often has to make additional efforts to collaborate with
professionals in the community because the family care provider acts as the administrator, secretary, purchase officer, and teacher (Freeman & Vakil, 2004). In short, the family care provider (typically an individual caregiver) has all the responsibilities that a multitude of professionals have in a center based child care program (Freeman & Vakil, 2004). The attitudes and perceptions of professionals makes a huge difference when it comes to providing early intervention services to children with special needs (Freeman & Vakil, 2004).

Parental Perceptions, Attempts to Obtain Services

The literature on parental perceptions on obtaining services for their child with special needs is limited to only a handful of articles available. However, despite the paucity of literature available, there are a few themes that emerge. These themes include: (a) parental confidence level in obtaining services for their children and helping their child learn (Paradice, et al., 2007; Raspa et al., 2010); (b) parental confident in knowing how to obtain services for their children in spite of the child’s disability (Paradice et al., 2007; Raspa et al., 2010) and (c) parental frustration with pediatricians taking parents’ concerns seriously (Hendrickson et al., 2000; Raspa et al., 2010).

Parental Confidence Level

Parents were very confident in their ability to support their child and understanding their child with special needs (Raspa et al., 2010). The findings of Raspa et al. (2010) corroborated with those of Paradice et al. (2007) also found that parents understood their child and the child’s ability. Meaning, prior to participating in a study, parents thought they fully understood their child and were able to meet their child’s needs. However, after participating in studies, parents knew how to better obtain services
for their child (Paradice et al., 2007; Raspa et al., 2010). This is important because parents better understand how to navigate the system. Parents can better obtain services for their child because they are better informed on how to obtain services.

*Parental Confidence in Knowledge of Obtaining Services*

Some families also indicated they did not know how to obtain services for their children and did not know their rights and the rights of their child (Hendrickson et al., 2000; Nolan et al., 2007; Porterfield & McBride, 2007; Raspa et al., 2010). Porterfield & McBride (2007) and Raspa et al. (2010) both found that family income correlated with having knowledge of obtaining services for children with disabilities. More specifically, the lower the income of parents, the lower the knowledge about obtaining services. Low income families were less likely to say they needed services (Porterfield & McBride, 2007). Furthermore, Nolan et al. (2007) indicated that parents were never or rarely informed about services in their community thus hindering them from obtaining services. Finally, Hendrickson et al. (2000) reiterated the lack of parental confidence in obtaining services because inadequate information was available to parents. The lack of information about community services available to children with disabilities and their families falls into the exosystem of Bronfenbrenner’s (1986) ecological model. Other than limited information about services in the communities, families also expressed frustration with pediatricians in the community.

*Parental Frustrations with Pediatricians*

The most surprising finding from the literature, from the perspective of the reviewer of this literature, is the number of parents who rely on their child’s physician to help when they have a concern about their child’s development. Parents reported being
ignored by their child’s physician and indicated that the physician was unaware of how
the parent could find or obtain services for their child (Hendrickson et al., 2000).

Parents are relying on the pediatrician as a first contact to services when parents have
concerns. After reviewing several premedical education requirements from the
University of Washington, Cornell University, and the University of Louisville, no child
development courses were mentioned. When looking at requirements for pediatricians,
specific courses related to child development were not mentioned. According to the
University of Maryland Medical Center (2007), pediatricians:

provide preventive health maintenance for healthy children; medical care for
children who are acutely or chronically ill. Pediatrists manage the physical,
mental, and emotional well-being of their patients, in every stage of development
-- in good health or in illness. Additionally, pediatrists are concerned with more
than physical well-being. They also are involved with the prevention, early
detection, and management of other problems that affect children and adolescents,
including: behavioral difficulties; developmental disorders; functional problems;
social stresses; depression or anxiety disorders. Pediatrics is a collaborative
specialty -- pediatricians work with other medical specialists and healthcare
professionals to provide for the health and emotional needs of children. (n.p.)
CHAPTER VI

CONCLUSION

Parents of children with special needs most often require additional support from that of typically developing children. While parents are experts on their own child, parents of children with special needs are not experts on providing services for their child. The literature indicates that some parents are not aware of how to obtain services for their child and many do not know that their community provides services for children with special needs (Applequest, 2009; Nolan et al., 2007; Raspa et al., 2010). Parents who reported being part of an early intervention team reported positive findings regarding their confidence in obtaining services for their child and reported positive outcomes for their child receiving early intervention services (Grascon et al., 2010; Lyons et al., 2010).

The information obtained from the literature is vital to help service providers and other professionals. However, more research that specifically targets the struggles parents have in coordinating services from early intervention to the school system is needed. The literature is limited in this area and information obtained will help professionals and service providers assist families to make a seamless transition from early intervention programs to the school system.
CHAPTER VII

PRACTICE RECOMMENDATIONS

Research findings are vital to professionals and practitioners alike; the research indicates that current practices or policies require changes. Based on the literature review examining parental perceptions of obtaining services for their children with special needs, there are a few changes needed to the current way professionals provide services to families of children with special needs. According to Applequist (2009), Nolan et al. (2007), and Hendrickson et al. (2000), families were not aware of services in their communities or did not know how to obtain the services provided. Therefore, it is recommended that information about services provided to people with special needs become more readily available in the community. This knowledge needs to be as common among community members as the location of the local bank or library. According to the ecological model, families depend on information from their community (Bronfenbrenner, 1986) and having knowledge about services readily available to all community members will help families have better access to information or services. This could be easily provided to families through community child care centers, community centers, libraries, utility offices, and state and federal offices as well as public service announcements on TV and the use of billboards.

Additionally, research by Hendrickson et al. (2000) indicates that parents first mentioned their concerns regarding their child’s development with the child’s pediatrician. Hendrickson et al. (2000) found that all mothers in their study reported they did not feel their child’s doctor took their concerns seriously. Moreover, one parent reported they had no confidence in their child’s pediatrician because of previous
experience with an older child with special needs (Hendrickson et al., 2000). It is unknown why this mother did not obtain services from another pediatrician. The research findings of Hendrickson et al. (2000) indicate that practice recommendations be changed in the pediatric field. These findings suggest that pediatricians need additional education in the area of child development or that pediatrician’s offices need to provide access to a child development expert or early intervention expert to address parental concerns regarding child development.
CHAPTER VIII
POLICY RECOMMENDATIONS

Changes in policies for parents obtaining services for children with special needs must also be addressed. As previously mentioned, this literature review has revealed barriers parents are faced with when trying to obtain services for children with special needs. Based on the research of Applequist (2009), Nolan et al. (2007), and Hendrickson et al. (2000), the first policy recommendation is in regards to pediatricians and other medical professionals. Families indicated not being taken seriously by pediatricians when expressing concerns about their child’s development; based on these indicators, pediatricians and other medical professionals should be required to refer families who express concerns regarding their child’s development to state early intervention agencies or school systems for further evaluation and possible testing. The family stress theory states “if people define their situation as real, it is real in its consequence” (Zimmerman, 2001, p. 313). Therefore, pediatricians and professionals need to acknowledge parents’ concerns.

According to the family stress theory (Hill, 1949), parental concerns about their child’s development are real to them even if pediatricians do not see the same signs parents see, therefore, a policy change for additional screenings when parents express concern may help to ease family stress. Zimmerman (2001) states that satisfaction is often used to “measure individual and family well-being” (p. 320) and research of Applequist (2009), Nolan et al. (2007), and Hendrickson et al. (2000) indicate low to nonexistent satisfaction with pediatricians and access to services. Policy changes requiring additional screening and evaluation of children with special needs would not
only acknowledge parental concerns but also could increase parental satisfaction with the medical community.

The ecological model must be reviewed when examining services available in the community (Bronfenbrenner, 1986). In the ecological model, Bronfenbrenner (1986) discusses the components of the system and how the system functions. If families are not aware of services available in the community, the families are not able to obtain these services. Consequently, when families living in communities are not aware of services available, then the family is not able to obtain these services, thus, the child is not receiving services at the earliest stage possible. Bronfenbrenner, tells researchers to think inside the box; the same can be said for service providers. If service providers think inside the box, the ecological box that is, then information about services in communities would be better provided to families. Every component in the community either directly or indirectly affects the family (Bronfenbrenner, 1986). Thus, as professionals, we need to ensure that families have access to information regarding services provided in their community. This information could be easily made available to parents through local medical service providers, school systems, child care providers, local libraries, utility service provider (electric, water and gas service providers), and local and state offices.

This review of literature focusing on barriers parents face when trying to obtain services and confirms that the struggles Eric’s mother had with obtaining services was not a rare occurrence, it is almost the norm. Shedding light on barriers parents face may help other parents like Eric’s to have an easier time obtaining services for their child. The writer expected Eric’s situation to be a rare occurrence; however, the literature reveals a different story. Parents do face barriers when obtaining services for their
children. Some of these barriers are in the policies designed to help families.

Additionally, if Eric was not in a program that understood and knew the laws for providing services to him, Eric and his mother may have been like other parents in the literature – struggling to find services he needed.
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