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Beyond The Barriers: A Qualitative Investigation Into The Experiences Of General
Pediatricians Working With Young Children Exhibiting Developmental Delays And
Disabilities

by

Kahlila Genese Mack

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Psychological and Social Foundations
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Keywords: aap guidelines, school psychologists, educators, full-service schools,
qualitative

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Dedication

This dissertation is dedicated to all graduate students...

“It’s not how you start, it’s how you finish.”

–unknown author

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Beyond the Barriers: A Qualitative Investigation into the Experiences of General Pediatricians Working with Young Children Exhibiting Developmental Delays and Disabilities

Kahlila Genese Mack

ABSTRACT

General pediatricians are typically the first professionals to detect the early developmental concerns of young children during their infant and toddler stages. When concerns are identified by the general pediatrician, best practice encourages the referral of young children for further assessment and/or intervention. Due to these factors, this study focused on the methods general pediatricians use in their efforts to implement the American Academy of Pediatrics (AAP) guidelines for the developmental surveillance and screening of young children. Furthermore, this study focused on the barriers faced by general pediatricians and the solutions they have developed to overcome these barriers in their efforts to assist young children with developmental delays and disabilities.

Twenty-eight pediatricians who also were members of the Region V Florida Chapter of the AAP provided responses to survey data inquiring about the implementation of AAP guidelines within their settings. Six of the survey respondents were general pediatricians who each participated in a semi-structured interview to gain further insight into their implementation of the AAP guidelines. Additionally, existing barriers were examined to determine the strategies general pediatricians developed to overcome them. The results showed that each of the six general pediatricians reported their engagement in some, if not all recommended AAP guidelines. The general pediatricians shared specific examples of how this was done, which provided valuable data for other general pediatricians who desire to learn effective strategies for

implementing AAP guidelines.

The interview responses addressed several themes, including training and continuing education, learning about and using developmental screeners, determining the cause of delays and disabilities, referring children with delays and disabilities, using a culturally-sensitive/family centered approach, and increasing parent awareness. General pediatricians also reported how they have overcome the barriers (e.g., limited time and staff members) to following AAP guidelines, as well as barriers that continue to exist (e.g., insufficient reimbursement for preventive care, difficulties serving children from low-income families, etc.). Although this study focused on how general pediatricians have overcome obstacles, multidisciplinary collaboration was emphasized as an integral factor needed to achieve the earliest identification and intervention implementation for young children with developmental concerns.

Chapter One

Introduction

Statement of the Problem

The early years of a child's life are crucial for cognitive, motor, language, social, and emotional development. Children whose developmental concerns remain unidentified face an increased risk for compromised health, safety concerns, and developmental delays (Center for Disease Control and Prevention, 2005). Sices (2007) reported that delays in the development of speech and language, fine and gross motor, social, and problem-solving skills in early childhood are indicators for specific developmental conditions (i.e., speech and language disorders, learning disabilities, cognitive disabilities, autism spectrum disorders, cerebral palsy, and vision or hearing impairments). The 2003 National Survey of Children's Health showed that children having chronic problems were impacted by diminished family functioning, increased school absences, and less participation in community activities compared with their peers. Additionally, this survey noted that the most commonly diagnosed problems were learning disabilities (11.5%), attention-deficit/hyperactivity disorder (8.8%), and behavioral problems (6.3%) among children (i.e., ages 6 through 17 years of age) in addition to speech problems (5.8%) and developmental delays (3.2%) among preschool-aged children (Blanchard, Gurka, and Blackman, 2006).

There is substantial evidence demonstrating that early intervention services (e.g., Head Start programs) produce positive effects regarding the developmental outcomes of

children who are at risk for or have delays and disabilities. With early intervention efforts, young children may attain skills in various domains (e.g., cognitive, language, social, etc.) that are necessary for their educational achievement. It is imperative that developmental concerns are addressed as early as possible for a young child, to ensure that later school concerns (e.g., low self-esteem, retention, etc.) may be potentially avoided. Positive outcomes regarding children's physical, social, emotional, language, and cognitive development as a result of involvement in early intervention programs have been clearly documented. However, in order for these children to obtain appropriate early intervention services, it is imperative that they are not only identified, but also referred in a timely manner by health care providers, such as general pediatricians.

Within the healthcare profession, several factors have made the process of early identification and timely referral of young children with delays and disabilities difficult, due to barriers often faced by general pediatricians. Examples of these barriers include unfamiliarity with screening tools used to detect developmental delays, insufficient time to administer these tools during office hours, a lack of nonphysician staff to assist with developmental screening, difficulties obtaining reimbursement for preventive services (Perrin, 1999; Sices, Feudtner, McLaughlin, Drotar & Williams, 2004; Halfon et al., 2004), a lack of knowledge regarding community resources available for intervention (Perrin, 1999), and feelings of inadequacy regarding the knowledge required to conduct thorough developmental and behavioral screenings upon ending residency training (Frazer et al., 1999; Perrin, 1999).

General pediatricians are the key professionals who can assist in closing the widening gap of children who lack services for developmental concerns. King and

Glascoc (2003) noted that general pediatricians have the unique opportunity of assisting with the improvement of children's developmental outcomes via early identification and referral of children who are at-risk for delayed developmental outcomes. For example, general pediatricians often assess preschool-aged children (i.e., children less than five years of age) during preventive-care visits (Sices et al., 2004). Therefore, general pediatricians typically have several opportunities to identify developmental concerns and initiate the early intervention process.

Rationale for the Study

General pediatricians assess children for medical and/or developmental concerns, as well as the prevention, diagnosis, and treatment of children's illnesses. However, early identification and referral of children with developmental problems continues to pose a challenge considering the many barriers faced by general pediatricians. This issue has led the researcher towards seeking answers that may assist general pediatricians in identifying children with delays and disabilities early, as well as refer for early intervention services.

The American Academy of Pediatrics (2006) published updated guidelines for developmental screening in a July policy statement entitled, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening." Recommendations include becoming educated about developmental issues, risk factors, screening techniques, and community resources that are needed to assist with consultation, referral, and intervention implementation. Although recommendations have been provided, some general pediatricians continue to struggle with implementing these suggestions (King & Glascoe,

2003). Therefore, one may consider the possibility that some general pediatricians need to be informed on *how to* implement these recommendations within their practice, instead of simply having knowledge of them. Specifically, general pediatricians may be in need of practical answers from colleagues who have experience with identifying developmental delays and risk factors in a manner that complies with the AAP's recommendations. An examination of these responses may assist general pediatricians with answering the question, "*How can I overcome barriers to the early identification and intervention of young children with delays and disabilities within my practice?*"

Purpose of the Study

The purpose of this study was to understand the process used by general pediatricians who adhere to the AAP guidelines regarding the identification and referral of young children with delays and disabilities. It was the researcher's goal to discover the specific strategies and procedures implemented by general pediatricians who have followed these guidelines. Furthermore, the researcher's goal was to determine what thought processes, events, and actions have helped these general pediatricians conquer presenting barriers to early identification and referral for intervention services, as well as their thoughts on why some barriers have continued to exist. The researcher sought to provide in-depth and detailed examples from general pediatricians within this qualitative study that may help others overcome similar barriers.

Research Questions

The current study documents the experiences of general pediatricians within the West Central Florida area, who work with children having developmental delays and disabilities. The following research questions were proposed for this study:

- 1) What strategies and procedures are general pediatricians implementing (e.g., using developmental screeners to identify children's needs, referring children in a timely manner to intervention services within the community, etc.) to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?
- 2) What specific barriers have general pediatricians encountered and overcome in an effort to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?
- 3) How have general pediatricians overcome these specific barriers in an effort to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?
- 4) Which specific barriers continue to prevent general pediatricians from effectively screening, diagnosing, referring, and/or case managing children with developmental delays and disabilities?
- 5) In what ways are general pediatricians collaborating with other professionals (e.g., early interventionists, teachers, school psychologists, etc.) in an effort to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?

Importance of the Study

In addition to the health field, there also is a longstanding emphasis on prevention and early intervention services for young children within the field of early childhood special education (ECSE) services. Several disciplines (including the researcher's field of school psychology) focus on meeting the needs of young children in the area of early

intervention (Peterson & Luze, 1996). Wilen (2003) indicated that there are an increasing number of children entering the school system having delays and disabilities. Crockett (2004) discussed the critical issues faced by children, which interferes with their successful development. Specifically, a total of 37% of children in the U.S. live in low-income families, which may influence the types of resources available to their families. By the time these children enter kindergarten, they often are behind their peers and may need much assistance from their teachers and other school staff in an effort to help them “catch up” to their peers. However, it is possible that if some of these children were identified early and received consistent services before entering the school system, valuable time would have been salvaged and school and community services could focus on the continuation of supportive services for these children. Additionally, information obtained by general pediatricians regarding these children’s early experiences could inform other professionals as to the nature of concerns previously faced by the child, well as the effectiveness of early intervention efforts.

The early intervention and referral of young children for intervention services by general pediatricians also may reduce the number of children in need of intensive interventions specifically meant to meet their individual needs (i.e., Tier 3 services) during the later school years. For example, students who come from low-income backgrounds (e.g., African American students), are often overrepresented in special education classes and classified as educable mentally handicapped (EMH), which is a highly restrictive and self-contained educational setting (Mack, 2004). It is this type of intensive service that could potentially be avoided with the timely identification of concerns and implementation of early intervention services for young children at-risk for

developmental concerns.

Overall, this study adds to the current research base by providing real-life accounts of how a sample of general pediatricians overcame the barriers to identifying and referring young children within their practices. Instead of simply stating the barriers and recommendations for overcoming them, this study provides detailed and practical answers of how each general pediatrician *has* overcome them, as well as the barriers that have continued to pose challenges. The researcher desired to provide answers that would lead to possible changes in policy regarding longstanding and systemic barriers, increased collaboration among professionals, and further opportunities for the continuing education of healthcare and educational professionals regarding this topic.

Chapter Two

Literature Review

A Case for Concern - Children with Developmental Delays and Disabilities

Throughout this review of literature, several topics regarding the early identification and early intervention of young children with developmental delays and disabilities are discussed. This research review begins with a definition of developmental delays and disabilities, and addresses the prevalence of children with these concerns. Additionally, the causes of these developmental concerns, suggested strategies for identifying and intervening early, and the difficulties pediatricians often have when seeking to achieve the goals of early identification and intervention are discussed.

Definition of Developmental Delays and Disabilities

Prieto (2002) indicated that developmental delays and disabilities occur when a child fails to reach specific developmental milestones around the time expected for same-aged peers. Specifically, definitions state that a developmental delay occurs when there is a 40% delay within a single developmental domain (e.g., communication) or there is the presence of 25% delays in two or more areas of development (e.g., communication, cognitive, and fine motor). Furthermore, a global delay occurs when there is a significant delay in two or more developmental domains. The number of infants and young children with developmental delays within the general population has shown a notable increase in occurrence over the past 20 years (Prieto, 2002). The developmental delay becomes a disability when there is consistent failure in attaining these milestones, which results in

impaired functioning. The goal is to prevent the occurrence of a stable disability within developmental domains (e.g., behavior, cognitive, social-emotional, etc.) via early identification of developmental problems and the implementation of early intervention services.

Approximately 40 years prior to date, young children with developmental disabilities experienced inadequate care and ineffective services to assist with their concerns. In fact, these children were often ignored and even isolated from the general population due to their various conditions (e.g., mental retardation) until the enactment of the Education for All Handicapped Children Act in 1975. This act was the impetus for the development and implementation of early childhood demonstration projects and programs. Currently named the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, children with delays and disabilities may be identified starting at infancy, with entitlement for special education services beginning as early as three years of age. Additionally, IDEIA 2004 supports the No Child Left Behind Act of 2001 and addresses principles of the law such as evaluation procedures, early intervention services, and funding issues (Gartin, 2005). These regulations are pertinent to those within the educational profession, such as school psychologists, who are particularly invested in ensuring that children receive the best academic and behavioral support services that are available. The National Association of School Psychologists (NASP) defined school psychologists as individuals with specialized training in psychology and education, and who also use their training to collaborate with parents, educators, and other professionals in an effort to facilitate a children's learning within healthy, supportive, and safe environments (Fagan & Wise, 2000). Additionally, school psychologists have experience

with prevention, assessment, intervention, and consultation activities for children of all ages and developmental levels (Fagan & Wise, 2000).

School psychologists often encounter children with developmental delays and disabilities within the educational system. Due to the influx of children continuing to need frequent and intensive intervention services, it is important that school psychologists identify concerns as early as possible. School psychologists often identify students with developmental delays and disabilities and link them to the necessary educational services. However, the early identification and early intervention of developmental concerns would be even more effective, in some cases, if it occurred earlier in the child's development. For example, most children will be seen by their pediatrician several times throughout their early years during well-child visits, before ever meeting a school psychologist. Therefore, the pediatrician is the most likely professional to assess early developmental concerns (Sices, et al., 2004). What is unknown is the degree to which general pediatricians have the resources available to them to fulfill the role of early identification and referral for children who are at-risk for or exhibiting developmental delays and disabilities (Sices et al., 2004).

Prevalence of Children with Delays and Disabilities

The early childhood years have a critical influence on later outcomes of school-aged children. Prevalent issues among children, such as learning disabilities, speech and language impairments, and mental retardation, are often related to early developmental problems (Dworkin, 2001). Sices et al. (2004) reported that approximately 17% of children under the age of 17 years living within the United States have been diagnosed with at least one disability and approximately 30% of this population is known to have

multiple disabilities. Sices et al. (2004) also stated that young children with developmental delays are often under-identified and under-served. Specifically, between the years of 1999 and 2000, only 1.8% of children under the age of three received early intervention services, while approximately 5% of preschool-aged children received intervention services. Furthermore, a study published in the *Journal of Policy and Practice in Intellectual Disabilities* examined the reasons why infants and toddlers entering Part C early intervention services are eligible according to reports given by service providers. Results showed that 62 percent of infants and toddlers were eligible because of developmental delay, 22 percent were eligible because of a diagnosed condition, and 17 percent were eligible because they were at risk for developmental delay (Scarborough, Hebbeler, & Spiker, 2006).

Causes of Developmental Delays and Disabilities

Berk (2000) indicated that causes of developmental problems are often connected to conditions or exposure to teratogens, which arise during the prenatal, perinatal, and postnatal periods of development. The age of the fetus, dose of the teratogen, and genetic makeup of fetus and parent all influence the child's development. Prenatal risks include developmental conditions that arise due to a genetic and/or an environmental origin (e.g., chromosomal abnormalities, infections due to maternal conditions, etc.). For example, a child's prenatal exposure to teratogens such as aspirin, tobacco, alcohol, cocaine, crack, heroine, and marijuana may cause harmful effects in their development such as prematurity, low birth weight, cognitive difficulties, poor motor coordination, behavioral problems, and/or facial abnormalities (such as those seen in children with fetal alcohol syndrome/effects). Consistent exposure and/or exposure to a combination of teratogens

may even cause death. Perinatal risks include conditions such as intracranial hemorrhage and asphyxia, which extend from the seventh month of pregnancy to the first 28 days after birth. Finally, postnatal risks consist of conditions that begin after the first month of life, including respiratory disorders, nutritional deficiencies, and accidents (Knopp & Krakow, 1983). Berk (2000) also noted the effects of pollution, a postnatal factor, in industrialized nations and inner-city areas where chemicals such as mercury and lead are released into the atmosphere, therefore causing deleterious health concerns. Overall, Berk noted that teratogens can have harmful effects on a child's development by influencing prematurity, low birth weight, brain damage, physical defects, and even death.

Many teratogens have been known to especially impact children from poverty areas within the country. Poverty negatively affects a child's functioning, especially young, developing children who persistently live in poverty, and children who live in extreme poverty conditions (Morris & Gennetian, 2003). In fact, poverty has the strongest, negative impact on a child's academic achievement (Duncan & Brookes-Gunn, 1997). Noble, Norman, and Farah (2005) stated that socioeconomic status (SES) is strongly associated with cognitive ability and achievement during childhood and throughout adolescence. For example, Halle, Kurtz-Costes, and Mahoney (1997) reported that children who live in poverty score lower on standardized achievement tests and are less likely to finish high school, attend college, and pursue postgraduate education when compared to their more advantaged peers. Poverty also can have negative effects on a child's health, therefore affecting his or her cognitive development. Pollitt (1994) reported that poverty areas within the United States and low-income countries have high percentages of infants with anemia, which is linked to poor performance on mental and

motor tests among infants and children. Pollitt further noted that there exists evidence from the United States and developing countries suggesting a negative impact of concurrent illnesses and poor nutrition on a child's learning in school.

Unfortunately, individuals living in poverty have more exposure to various teratogens, such as drugs and environmental hazards, than individuals not living within these environments. Additionally, individuals living in poverty have limited access to resources (e.g., finances, healthcare, community programs, etc.) that can help them overcome their daily challenges (Morris & Gennetian, 2003). Parent factors correlated to poverty that also influences children's development are mental and physical health, as well as education level (Prieto, 2002).

The Importance of Early Identification and Intervention

Dworkin (2001) indicated that the rationale for the early detection of developmental problems not only relies on the fact that a child's early years affect later school success, but also that addressing problems early can avert the occurrence of secondary problems (e.g., low self-esteem). Wilen (2003) noted that many children often arrive to school settings lacking the necessary intellectual, social, emotional, and language skills that are necessary for them to benefit from the educational system. Sandler et al. (2001) explained that early intervention services are developed for children from birth to three years of age, who demonstrate a developmental delay within their physical, cognitive, communication, social, emotional, and/or adaptive development, in an effort to prevent later school failure.

Federal mandates. The 2004 Individuals with Disabilities Education Act (IDEA) Reauthorization, states that all individuals with disabilities have access to a free and

appropriate public education (Silverstein, 2005). Within Part C of this Act, requirements for infants and toddlers are noted as it refers to early intervention services. In particular, Part C requires that all states have a “Child Find” system to ensure that children are being properly identified and evaluated. Child Find typically maintains contact with primary referral sources such as hospitals, childcare programs, physicians, parents, local education agencies, and social service agencies (National Center for Medical Home Initiatives for Children with Special Needs, 2003). There are specific requirements to provide services for infants and toddlers (birth to age three) with disabilities and their families. Among these requirements are evaluation and eligibility determination, the development of Individualized Family Service Plans (IFSPs), and service coordination for early intervention. Furthermore, related laws such as the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 maintain protections against the discrimination of children with disabilities (Walsh, Smith, & Taylor, 2000).

The Head Start Act addresses the responsibilities of childcare professionals serving children with disabilities who are in Head Start and Early Head Start programs (Walsh, Smith, & Taylor, 2000). Finally, the Division for Early Childhood (DEC) is known for its dedication towards developing and promoting policies and procedures to further support mandates for children with disabilities and their families. The core responsibility of the DEC is to identify recommended practices in early intervention for young children birth through five years. Some of the values and beliefs upheld by the DEC involve maintaining respect for children and families; implementing high-quality, comprehensive, coordinated, and family-centered services; and ensuring that all children participate actively within their family and community environments (Sandall, McLean,

& Smith, 2000).

Identifying Children with Developmental Concerns

The general pediatrician's role. General pediatricians play a very vital and influential role in the lives of children and families. They are familiar with child health and developmental concerns, and have the ability to consult with various child healthcare providers in an effort to refer children and families to the appropriate services. General pediatricians often have the ability to set the standard of care within their communities concerning the treatment of children with delays and disabilities (Sandler et al., 2001). Additionally, general pediatricians serve within a unique position allowing them to routinely see children less than five years of age for preventive care visits and facilitating the identification and referral of young children with developmental delays in a timely manner (King & Glascoe, 2003).

Family involvement. Research has shown that there is a strong relationship between parents' concerns and their children's developmental status, demonstrating a strong need for general pediatricians to effectively communicate and collaborate with families to address the service needs of children (Glascoe, 2000). Parents and caregivers are extremely vital in providing information on their child's developmental history and current language, cognitive, motor, and social-emotional development. In fact, systematically gaining parents' perspectives regarding their child's development is considered an effective method of identifying young children with developmental problems, in addition to being the least costly short term developmental screening approach (American Academy of Pediatrics, 2006). Glascoe and MacLean (1990) stated that parents' appraisals of their child's development can assist healthcare professionals

with identifying concerns. Additionally, the authors reported that parents whose concerns involved speech, language, cognitive, or fine motor issues, had children with an 80% chance of failing standardized developmental screening tests. The American Academy of Pediatrics (2006) indicated that the early diagnosis of disabilities, such as autism, is dependent upon obtaining parental concerns about their child's development, followed by a careful interpretation of those concerns. Glascoe (2000) reported that parental concerns related to children's hearing are strong indicators of hearing problems.

One way of systematically eliciting parental concern is by utilizing parent report measures. Parent report measures may be completed independently by parents. Barriers to using parent report measures include poor parental reading skills and/or language difficulties. However, these issues can be easily solved via alternative methods, such as the oral administration of the measure by a professional or using a translated tool (American Academy of Pediatrics, 2001a). Additionally, the use of technology during well-child visits and other screenings was considered effective in obtaining parent concerns and enhancing their knowledge, while facilitating a timely visit. For example, Sanghavi (2005) supported the use of an educational kiosk containing interactive and computerized tutorials that solicited child information, produced computerized summary reports, and provided anticipatory guidance for parents living in an impoverished county of New Mexico. This intervention method was found to further increase parent knowledge as compared to the use of printed materials alone. Overall, research has shown the importance of including the viewpoint and experiences of parents and caregivers when assessing their child's developmental status (American Academy of

Pediatrics, 2006). Table 1 provides a detailed list of a few parent report measures currently used by general pediatricians in practice.

Table 1. Parent Report Measures

	Parents' Evaluation of Developmental Status (PEDS)	Ages and Stages Questionnaire (ASQ)	Communicative Development Inventories (CDI)	Pediatric Symptom Checklist
Purpose	<p>Detects developmental and behavioral problems in children from birth to age eight</p> <p>Identifies children with and without delays</p>	<p>Screens infants and young children for developmental delays during 1st five years</p> <p>Provides a high percentage of correctly identified children with and without delays</p>	<p>Screens children 8 to 30 months in language and communication skills</p>	<p>Screens a broad range of emotional and behavioral problems that make up a child's psychosocial functioning. Used with preschool and school-aged children</p>
Time/Cost	Quick to administer and inexpensive	10-15 minute administration time and inexpensive	20-40 minute administration time and 10-15 minute scoring	Short, one-page questionnaire
Reliability/Validity	Demonstrates standardization, reliability, validity, and accuracy	Proven reliability and validity	Proven reliability and validity	Proven validity and high rates of sensitivity and specificity
Language	Available in Spanish	Available in Spanish, French, and Korean.	Available in English	Available in English

Surveillance and screening of developmental concerns. Developmental surveillance is a flexible, continuous process used by professionals who conduct skillful observations of young children during the provision of healthcare, while screening is a brief assessment procedure used to identify children who should receive a more comprehensive assessment or intensive diagnosis (American Academy of Pediatrics, 2006). Specifically, screening complements the surveillance process by detecting delays or disabilities through the periodic use of standard tools for all children (American Academy of Pediatrics, 2001a). Within both processes, healthcare providers such as general pediatricians can assist with early identification of children with a variety of concerns, including cognition, communication, motor, social-emotional, self-help or adaptive, sensory, and problem-solving skills (Yarbrough, 2001). Developmental surveillance and screening during well child visits would assist in helping healthcare professionals offer preventive guidance to families of children with developmental difficulties (American Academy of Pediatrics, 2001a).

According to the National Survey of Early Childhood Health conducted in 2000, 2068 parents of children aged 4 to 35 months of age reported whether recalled receiving a developmental assessment from their child's pediatric provider. Specifically, parents were asked to recall whether the pediatric provider had informed them that he or she was doing a developmental assessment and/or whether they recalled observing their child engage in tasks such as stacking blocks or throwing a ball. The results of this survey demonstrated that 57% of children 10 to 35 months of age received a developmental assessment. Also, 42% of parents recalled having their child's pediatric provider inform them that a developmental assessment was being completed. Furthermore, 39% of

parents recalled their child being asked to perform specific tasks routinely included in a developmental assessment (Halfon et al., 2004).

The American Academy of Pediatrics (2001a) noted that over the past several years, developmental testing by general pediatricians has been made easier through the development of efficient screening tools. The use of developmental screening tools is considered to be an efficacious way of identifying children with developmental delays (Sices et al., 2004). Screening tools can be specific to a disorder (e.g., autism), an area (e.g., cognitive, language, or motor development), or they may examine multiple areas of concern (Centers for Disease Control and Prevention, 2005, para. 1). Many tools are considered efficient, especially those that have adequate sensitivity, specificity, validity, and reliability, and have been standardized on diverse populations. Charman (2003) noted that “sensitivity” refers to the proportion of children with a disorder who are identified by the screening tool. “Specificity” includes the proportion of children without the disorder who the screening tool identifies as exhibiting normal development. Stringent criteria exist for screening tools to detect developmental concerns. For example, sensitivity is required to be high so that the screen misses few cases of the disability of concern, while specificity also is required to be high to prevent the identification of false positives. High validity of a screening tool demonstrates that the tool is measuring what it purports to measure, while a high level of reliability notes that the tool is consistently measuring a construct or domain (Yarborough, 2001). Screening tools with these attributes are recommended for use when determining a child’s level of skill and development (American Academy of Pediatrics, 2001a). Table 2 provides a detailed list of a few screening tools currently used.

Table 2. Screening Tools

	Bayley Infant Neuro-developmental Screener	Early Language Milestone Scale – Second Edition	CAT-CLAMS	Brigance Screens
Purpose	Screen infants at risk for developmental delay or neurological impairment. Also examines the auditory, visual, verbal, motor, and cognitive functions of children age 3-24 months.	Assesses speech and language development from birth to 36 months of age. Also examines auditory expressive, auditory receptive, and visual abilities.	Identifies developmental delays in children from 1-36 months of age. Also examines visual-motor functioning and expressive and receptive language	Screen used for infants through 90 months. Also examines speech-language, motor, readiness and general knowledge, and social-emotional, and reading and math skills.
Administration Time/Cost	10-15 minute administration time	1-10 minute administration time	6-20 minute administration	10 minute administration time and inexpensive
Reliability/Validity	-Test-retest reliability ranges from .71-.84 -Interrater reliability ranges from .79-.96 -80-88% classification agreement for children with developmental delays	Information not available	Information not available	High sensitivity and specificity for giftedness and developmental and academic problems Screens available in Spanish, Laotian, Vietnamese, and Cambodian
Language	Administered in English	Administered in English	Administered in English	

Guidelines for identifying developmental concerns. In addition to using validated screening tools when identifying concerns, specific guidelines have been established for general pediatricians and other professionals concerned with adequately identifying developmental concerns and providing services for children and families. According to Nickel and Desch (2000), there are general guidelines that physicians are to follow during well child visits in an effort to identify and refer children with developmental problems. First, it is suggested that physicians use a parent report measure to determine if there are any concerns. If warranted, a more thorough investigation of concerns may be conducted via screening the child to obtain information regarding current level of ability. If the information gathered from this screening indicates or validates concerns, it is the physician's role to consider the child's eligibility for early intervention services and then refer him or her accordingly. The authors noted that if no problems are determined at any point throughout this screening process, the physician should simply continue monitoring the child's development. Nickel and Desch (2000) stated that, in general, children should be screened at 4, 8, 12, 18, 24, 36, and 48 months during each well-child visit, which includes using informal observations and a review of parent concerns.

The medical home. General pediatricians are faced with several responsibilities involving their work with children having delays and disabilities. According to Sandler et al. (2001), there exists growing evidence that early intervention services have a positive impact on the developmental outcome of children with established disabilities, as well as children who are considered to be at-risk for disabilities. Implementing a "medical home" for a child is an ideal method used to encourage the appropriate case management of children's development. Within a medical home, a pediatrician is influential in providing

primary care for children and collaborating with the child's family and community professionals to identify and access all medical and non-medical services needed. The purpose of the medical home is to provide accessible and comprehensive primary care services, while simultaneously creating a family-centered, compassionate, and culturally effective environment for children and families. Strictland et al. (2004) operationalized the medical home concept using 5 components: 1) having a usual place for sick/well care, 2) having a personal doctor or nurse, 3) experiencing no difficulty in obtaining needed referrals, 4) receipt of needed care coordination, and 5) presence of family-centered care. Both the American Academy of Pediatrics and the American Academy of Family Physicians indicated the implementation of the medical home as best practice (Cooley, 2004). Barriers to implementing medical homes include a lack of knowledge about the medical home concept, a lack of professional time and office personnel to assist with implementation, and a lack of reimbursement for care coordination services (Nickel, Cooley, McAllister, & Samson-Fang, 2003).

The general pediatrician's office is the only place where most young children under the age of five years are seen for preventive care visits, therefore making the pediatrician's role ideal for conducting developmental screenings (Sices et al., 2004). When general pediatricians collaborate with families and early intervention services, they are able to provide a medical home for children with special needs and services (Sandler et al., 2001). Within the medical home approach, high quality and cost-effective health care is provided by the pediatrician who works in a partnership with the family. This care is continuous, coordinated, and comprehensive (American Academy of Pediatrics, 2002). Within this team, general pediatricians provide leadership for the medical home and as a

member of the early intervention team by consistently reviewing and renewing child goals and consulting with the family, therapists, and other service providers within the community to ensure the best care for children with developmental delays and disabilities (Sandler et al., 2001).

Cooley (2004) reported that no studies regarding the outcomes applying the medical home concept exist. Although, surveys have been completed to understand the parental perspective on the effectiveness of the medical home. For example, Palfrey, Sofis, and Davidson (2004) reported family satisfaction with primary care using a medical home model (i.e., Pediatric Alliance for Coordinated Care). Outcomes showed high levels of parent satisfaction care provided by the medical home for children with health and developmental conditions rated as “severe”. Also, there were significant decreases found in parental absence from work and in hospitalizations for their children. Additionally, the National Survey of Children with Special Health Care Needs showed that children without a medical home were twice as likely to delay receiving needed care and to have continued, unmet healthcare needs (Strickland et al., 2004). Despite the usefulness of medical homes and their ability to provide services to families with children having developmental delays and disabilities, certain barriers exist that make it difficult for general pediatricians to identify concerns, refer children to intervention services, and maintain continued collaboration with other childcare professionals. Some barriers are child and family-specific, while other reported barriers are related to the pediatrician, office, or the broader field of pediatrics.

Barriers to Early Identification and Intervention

Identifying concerns and referring for early intervention services. Barriers to the

early identification and referral of children with developmental delays exist within the general pediatrician's daily routine and within the nature of assessing a child's developmental status. For example, child development is a process which entails the occurrence of both growth spurts and stalls, which makes it difficult to pinpoint a child's developmental level at any given time. Therefore, many general pediatricians may seek the presence of clear-cut delays before a referral is made, to decrease the occurrence of false positives (King & Glascoe, 2003). Making the decision to wait for the presence of a clear-cut developmental delay may, in turn, impede the intervention process with children in much need of services.

Sices et al. (2004) conducted a mail survey with family physicians and general pediatricians to determine their practices when identifying children with developmental delays during preventive care visits. The sample consisted of 1600 practitioners (800 family physicians and 800 general pediatricians) from among all practicing U.S. physicians within the American Medical Association Physicians' Data File. The findings of this study demonstrated that most physicians (both general pediatricians and family physicians) elicited the presence of developmental problems by using lists of developmental milestones and/or the verbal prompting of parental concern, although this verbal prompting did not include the use of validated instruments. In fact, less than 15% of the physicians in this study used parent-completed questionnaires which have been proven reliable and timesaving. Finally, physicians reported themselves as the primary individuals responsible for developmental surveillance, which indicated that the use of other office personnel for this task does not occur often within the pediatricians' office. On the other hand, differences were seen between general pediatricians and family

physicians. Specifically, general pediatricians were more apt to use validated screening instruments when compared to family physicians, perceived a greater availability of community resources, and reported having higher self-efficacy in identifying developmental concerns (which may be attributed to their training) when compared to family physicians (Sices et al., 2004).

Although general pediatricians may consider themselves more competent at identifying developmental concerns when compared to family physicians, the 2000 American Academy of Pediatrics survey found that two-thirds of pediatricians did not feel adequately trained to conduct developmental assessments (Halfon, Regalado, McLearn, Kuo, & Wright, 2003). In fact, pediatricians reported spending most of their time with parents discussing typical concerns, such as immunizations, nutrition, and sleep issues. Furthermore, the Promoting Healthy Development Survey (PHDS) was created to assist providers, consumers, purchasers, and policy makers in assessing the degree to which health plans and practitioners provide recommended developmental services for children up to four years old. Results from the PHDS, which examined the quality of developmental services with a large population (N=3542) of Medicaid-enrolled children in Washington State, showed that approximately 50% of the parents reported having one or more insufficiently answered behavioral or developmental concerns after visiting their child's health provider (Halfon et al., 2003). Additionally, parent responses showed that 42% of the children within this population were at a high risk for developmental and/or behavioral delays, yet had not been identified as needing services.

Research has noted additional barriers to identifying delays and referring children for services that are both internal and external to the pediatrician's office (Halfon et al.,

2003). Specifically, pediatricians and patients typically endure a very short (e.g., approximately 10-15 minutes) well-child visit where parental concerns must be addressed as best (and as quickly) as possible. In one study, Lebaron, Rodewald, and Humiston (1999) noted the component parts of a typical well-child visit in minutes. The study was conducted with 164 children aged two years and younger, and took place with five pediatric practices and two public providers in New York State. Results showed that patients spent 16.3 minutes with the primary care physician, which included time for the physical examination, vaccination discussion, vaccine administration, and a discussion of other health concerns. Nurses encountered approximately 5.6 minutes with patients, also including time for a physical examination, vaccination discussion and administration, and a discussion of other health concerns. During the first year of life, six well-child visits are recommended. Additionally, the total time of well-child care ranged from 45 to 90 minutes during the first year of life, which declines each year after (Lebaron, Rodewald, & Humiston, 1999).

Other barriers consist of insufficient training in eliciting developmental and behavioral concerns and insufficient training administering standardized instruments. Most pediatricians rely on clinical judgment when assessing developmental concerns. However, the sole use of clinical judgment identifies less than 30% of children with mental retardation, learning disabilities, language impairments, or other developmental disabilities. Additionally, the use of clinical judgment identifies less than 50% of children with serious emotional and behavior problems (Glascoe, 2000). As a result, screening and assessment activities should be conducted by pediatric providers with the use of validated instruments (Halfon et al., 2004). However, general pediatricians and their support staff

frequently have little to no training in using standardized tools in the structured manner they are intended to be used, which poses the difficulty of accurately assessing a child's developmental status (American Academy of Pediatrics, 2001a).

Paying for the cost of these instruments also poses a concern for pediatricians, therefore, financial incentives aligned with the goals for improving preventive care services are needed (Halfon, Inkelas, Abrams, & Stevens, 2005). Another barrier involves the use of billing codes for the reimbursement of preventive care visits. Specifically, billing and payment for developmental services may need to be standardized (Halfon et al., 2005). According to AAP, the correct coding of services is necessary for increased efficacy and timely referral of children with developmental concerns (National Center for Medical Home Initiatives for Children with Special Needs, 2003).

Helping families transition to early intervention services. In addition to reimbursement factors, the costliness of instruments, and the time and skill needed to administer instruments and elicit developmental concerns, it has been noted that general pediatricians are often uninvolved in the process of assisting children and families with their transition to early intervention services. This may be due to general pediatricians having a lack of knowledge regarding the community resources available for assisting children and families (American Academy of Pediatrics, 2001a), as well as not having the office resources to facilitate this process.

For example, Silverstein, Grossman, Koepsell, and Rivara (2003) conducted a national study assessing the reported practices of general pediatricians on referring children to Head Start. Results showed that while 80% of general pediatricians discussed childcare placements with the families of preschool-aged children, only 14% of general

pediatricians were able to assist their families with the actual process of applying to Head Start. Barriers noted by general pediatricians regarding the lack of assistance provided to families who were applying to Head Start involved insufficient office time (77%) and a lack of nonphysician office staff to assist with the process (71%).

Considering that a lack of office time and non-physician staff are frequent barriers for most general pediatricians, service coordinators are often the individuals of choice for connecting children and families with community resources. Guralnick (2000) stated that service coordinators gather initial information from the family seeking intervention services for their child, in addition to other disciplines that the child may have contact with. Also, these coordinators assist with guiding families from the intake period, through the formal assessment period. After developmental evaluations have been completed, service coordinators are designated to assist with the development of the Individual Family Service Plan (IFSP) and help coordinate and facilitate early intervention services for children and families (Nolan, Young, Hebert, & Wilding, 2005). Some pediatricians (e.g., pediatricians working within a hospital or clinic) have contact with service coordinators who can assist them with referring children to the appropriate community programs. Collaboration with service coordinators is imperative to ensure that the child's care among providers is seamless. However, Nolan et al. (2005) examined reports of early intervention service coordinators' communication with medical professionals and found the opposite to this expectation. Results showed that 83% of the service coordinators noted that physicians did not provide input regarding the development of Individual Family Service Plans (IFSPs) for children with developmental delays and complex healthcare needs. Overall, it is imperative that general pediatricians are aware of

community programs for children, as well as maintain consistent communication with other childcare providers regarding their insights.

Overcoming Barriers - American Academy of Pediatrics (AAP) Recommendations

The AAP has developed recommendations for all healthcare providers working with infants and young children. These guidelines are to assist general pediatricians and others with screening for developmental delays and intervening with the identified children and their families within the framework of a medical home. It is assumed that as general pediatricians consistently follow these guidelines, the presence of barriers will decrease. According to the American Academy of Pediatrics (2001a), general pediatricians should do the following:

1. Maintain educated about developmental issues, risk factors, screening techniques, and community resources to assist with consultation, referral, and intervention.
2. Acquire the skills needed to administer and interpret valid and reliable developmental screeners.
3. Develop a strategy for providing periodic screening in the context of office-based primary care.
4. Present screening results to families using a culturally sensitive and family-centered approach.
5. Refer children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community.
6. Determine the cause of delays or consult with the appropriate consultant for determination.

7. Maintain relationships with community-based resources and coordinate care with them through the medical home.
8. Increase parents' awareness of developmental disabilities and resources for intervention.
9. Be available to families to interpret consultants' findings.

Additionally, the American Academy of Pediatrics (2001a) proposed three main recommendations that would assist general pediatricians in properly identifying and referring children with disabilities and their families. The first recommendation involves the screening and evaluation of infants with disabilities or who are at risk for developmental delays with the appropriate screening tools. The second recommendation implies that providers should refer children promptly for intervention services. The third recommendation suggests that providers obtain a medical etiologic diagnostic evaluation as appropriate.

Current Study

Despite the recommended goals that general pediatricians are to follow, barriers to working effectively with young children and families continue to exist within pediatric practice. However, there are cases where general pediatricians have overcome these barriers to the early identification and early intervention of children with developmental concerns. The current study sought to identify general pediatricians within the West Central Florida area who have implemented the AAP guidelines. The goal was to determine specific strategies general pediatricians have been able to implement within their practices to overcome presented barriers. Additionally, the researcher was interested in understanding which barriers, despite these strategies, continue to exist

within their practice. Specifically, insight was gained from pediatricians regarding their daily practices. Through the use of qualitative methodology, the researcher sought to understand the strategies implemented by general pediatricians within various environments, while simultaneously providing possible solutions for other general pediatricians who have sought to overcome similar barriers within their respective work environments.

Chapter Three

Methodology

Theoretical Framework

Social research involves a set of concerns or questions regarding the orientation of a researcher that supports a particular theoretical view (Carspecken & Apple, 1992). Within social research, qualitative research specifically focuses on the interpretation of personal experiences, the meaning of social phenomena, and the links among a larger number of attributes across relatively few cases (Bogdan & Biklen, 1992). Pope, van Royen, and Baker (2002) stated that qualitative research questions tend to be exploratory and the sample used is based on predetermined criteria in an effort to include a range of constituencies.

Design

A mixed-method design was used to address the research questions as both quantitative and qualitative information were needed. The quantitative information was obtained from the responses on the online survey entitled Young Children with Delays and Disabilities. Qualitative information was obtained through the development of an interview protocol, based on the online survey responses.

A collective case study approach (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005) was used for the interview portion of this study to note the experiences of general pediatricians. According to the authors, a collective case study takes place in multiple locations or documents the personalized stories of several similar or distinctive

individuals. Freebody (2003) stated that research utilizing multiple cases can add weight to the results by replicating patterns, which increases confidence in the robustness of the theory. Additionally, the cases within this study were considered exploratory, due to the researcher's attempt to ascertain information as to which factors have enabled general pediatricians to overcome barriers within their practices.

Within this study, the researcher sought to examine the experiences of general pediatricians in an effort to understand their unique and similar practices via semi-structured interviews (Gall, Borg, & Gall, 1996). Bogdan and Biklen (1992) noted that semi-structured interviews enable researchers to obtain comparable data across subjects. These interviews provide the flexibility and unstructured format of open-ended questioning, while also providing direction for the research that produces focused, qualitative, and textual data at the factor level. Semi-structured interviews can be used to clarify central domains and factors, operationalize factors into variables, and develop preliminary hypotheses about a topic. Using a semi-structured format within this study enabled the researcher to ask several specific questions, while utilizing follow-up probes to allow for the elaboration of topics.

Participant Recruitment and Sampling

The AAP is a professional membership organization of 60,000 primary care pediatricians, pediatric medical sub-specialists, and pediatric surgical specialists who are dedicated to the health, safety, and well being of infants, children, adolescents and young adults. The AAP also is composed of 66 regionally-based Chapters throughout the United States (American Academy of Pediatrics, 2008). One hundred and fifty pediatricians who are members of the Region V Florida Chapter of the American Academy of Pediatrics

(AAP) were selected to participate in an online survey created by the researcher for the purposes of this study (See Appendix D). Of these 150 individuals, 28 general pediatricians (19%) completed the online survey. Sandelowski (1995) stated that an adequate sample size in qualitative inquiry permits a deep, case-oriented analysis, yet results in a new and richly textured understanding of one's experience. Additionally, Sandelowski (1995) suggested that qualitative study directed towards discerning the nature of experiences includes approximately six participants. Furthermore, Pope, van Royen, and Baker (2002) noted that sample sizes for interview studies tend to be much smaller than those used in quantitative research. For this reason, one pilot participant and six study participants out of 28 who completed the online survey were interviewed due to the amount and complexity of information potentially obtained within each case study (Blaxter, Hughes, & Tight, 2001). Purposive sampling was used to select specific participants who implemented the American Academy of Pediatrics (AAP) best practices for the identification, diagnosis, referral, and/or case management of children with developmental delays and disabilities. Demographic variation also was utilized in an effort to include a sample of general pediatricians who worked in multiple settings (e.g., hospital, clinic, etc.), represented both genders and a variety of age ranges, and ranged in years practice within the field of pediatrics (Sandelowski, 1995).

Procedures

The researcher received approval to conduct this study through the Institutional Review Board (IRB) Division of Research Integrity and Compliance at the University of South Florida. After receiving the Board's approval to proceed with data collection, the researcher contacted a local pediatrician who also served as a past representative for the

Region V Florida Chapter of the AAP. This individual provided the researcher with email addresses to enable communication via email with the 150 pediatricians who were members of the Region V Florida Chapter of the AAP.

An introductory email was sent to the members of the Region V Florida Chapter of the AAP (See Appendix A). This email stated that the pediatrician had been selected to participate in an online survey examining his or her experiences with serving young children with developmental delays and disabilities. Furthermore, the email noted that seven pediatricians would be selected to take part in a face-to-face interview in an effort to gather additional insight regarding their experiences.

Phase one: online survey. After consulting with the researcher's committee members and the local pediatrician, an online survey was chosen as the most effective method for obtaining reliable feedback from general pediatricians regarding their willingness to participate in this study. The researcher created an online survey that was posted on Survey Monkey, a website known for assisting with the setup and hosting of surveys. This brief online survey entitled Young Children with Delays and Disabilities, assisted with gaining preliminary information about each pediatrician in an effort to select interview candidates.

Considering the Region V Florida Chapter of the AAP consists of all pediatricians (e.g., developmental pediatricians, general pediatricians, etc.), the researcher screened the demographic information provided by each individual in the online survey in an effort to only select general pediatricians. This study focused on general pediatricians because they specialize in the diagnosis and treatment of a variety of ailments specific to children, including ongoing assessment of growth and development. Overall, this survey inquired

about information regarding demographics, the implementation of AAP recommendations, and the barriers to successfully implementing AAP recommendations.

A follow-up email (See Appendix B) was sent to the 150 pediatricians, both one and two weeks after the initial email was sent, to help increase the response rate. This generic email thanked those who participated in the online survey and reminded those who had not yet participated to do so. This follow-up email included the following components recommended by Dillman (1978): tie to previous communication, recognize the importance of the survey, explain why the completion of the survey is important, discuss the usefulness of the study and the importance of recipients to the study's usefulness, and provide a reminder in addition to a note of appreciation.

The online survey consisted of four sections and took approximately three to five minutes to complete. The first section inquired about each pediatrician's demographic information (e.g., practice setting, years in practice, specific expertise, etc.). The second section inquired about the approximate percentage of time each pediatrician spends engaging in specific AAP recommendations. The third section identified the common barriers to implementing AAP recommendations. Finally, the fourth section informed the pediatrician that he or she *may be* selected to participate in an interview to gather additional information.

Phase two: selection of interview candidates. Upon receiving completed online surveys, the researcher screened the data for participants who were general pediatricians, and rank ordered each participant by the number of AAP recommendations implemented. The participants were rank ordered according to the number of AAP guidelines followed. The seven general pediatricians (i.e., six study participants and one pilot participant) who

ranked highest on these guidelines were contacted for participation within this study, while information from additional candidates was held in the event of attrition. The individual ranked seventh was chosen as the pilot participant.

A total of seven general pediatricians agreed to participate in a face-to-face interview. One interview participant encountered a scheduling conflict after agreeing to participate on a specific date and was unable to reschedule. Therefore, the researcher selected an additional interview participant who ranked the next highest for following the AAP guidelines from a list of potential participants. As an incentive for participation, each of the seven participants was informed that he/she would receive a restaurant gift certificate at the culmination of their interview.

Phase three: interview process. The researcher scheduled the interviews via email and/or phone communication with each interview participant. An informed consent document (See Appendix C) explaining the potential risks and benefits of participating in the study was provided to each interviewee prior to starting the interview. The participants were required to sign and date the informed consent document noting their willingness to participate. One interview participant was unable to make the face-to-face interview, although preferred to complete the interview via conference call. In this case, the researcher emailed the informed consent document to the interviewee. In return, the interviewee faxed the researcher a signed informed consent document and completed the interview via phone.

During the interview, the researcher had information regarding the AAP recommendations that the pediatrician had reported consistently implementing for the majority of his/her patients. Additionally, an interview protocol was utilized to facilitate

effective questioning during the interview (See Appendix E). The researcher also used the AAP and barrier checklists from the original surveys to ask each participant specific questions relative to his or her experience. For example, if the participant noted overcoming four barriers (e.g., obtain reimbursement for preventive services, administer validated screening tools, score validated screening tools, and refer families to community resources) on the online survey, the researcher formulated the interview protocol to specifically ask the general pediatrician how he or she had overcome these barriers. Additionally, the researcher queried the participant regarding the reasons why he or she had not been able to overcome the remaining barriers. Using this information, the researcher directly asked each interviewee questions and recorded their responses while using an audiotape and handwritten notes. An example of a prompt used to elicit additional information is, “You indicated that you have acquired the skills needed to administer and interpret valid and reliable developmental screeners. Tell me more about how you have been able to acquire these skills.” Another example of a prompt and follow-up questions asked to gather information for a topic is, “You indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community. Please explain the process you have implemented in order to do this in a timely fashion. What are the steps you take from well-child visit to referral? How did you become knowledgeable of the programs within the community?”

Bogdan and Biklen (1992) stated that when interviewing is the major technique for data collection within a study, a tape recorder is recommended. As previously stated, the participants were informed that data collection entailed an audiotaped interview

format to enable the researcher to accurately analyze the data. During this interview, the researcher also wrote key words and phrases stated by the participant as a back up to the tape-recorder. In an effort to validate implementation practices, the researcher requested to retain samples of permanent products (e.g., blank charts, screening protocols, etc.). After the interview, each participant was offered a gift certificate to dinner at a restaurant in the West Central Florida area.

The researcher utilized a pilot participant within this study in an effort to assist with familiarizing herself with effective questioning methods. During this interview, the researcher was observed by a research committee member familiar with semi-structured interview methods. Upon completing this interview, the researcher and committee member analyzed the interview process and information obtained. This consultation enabled the researcher to determine the feasibility of the questioning used during the interview and determine whether any parts of the interview process should be revised when conducting future interviews with the remaining participants. The committee member informed the researcher of several areas within the interview in which further information could have been obtained. Specifically, the researcher was instructed on methods of both listening and observing the interviewee in an effort to ask additional questions that would yield a more thorough explanation of his or her thoughts. Considering this was the first interview conducted by the researcher and areas of this interview had not been more fully explored, the pilot participant's data were not combined with data obtained from other general pediatricians within this study. Also, these data were not included in any subsequent analyses.

Data Analysis

Prior to data analysis, the researcher transcribed the recorded interviews while using Microsoft Word's voice recognition software. Using methods proposed by Bogdan and Biklen (1992), the researcher wrote the participant's number, date, and page number on each transcription so that each segment of text could be verified. Data transcription was completed by speaking words into a microphone that were automatically transcribed by the voice recognition software. Prior to using this program, voice training was necessary to ensure the accurate transcription. Consequently, the researcher was able to listen to the statements recorded, restate them into the microphone, and view the text on the computer screen for inaccuracies. After transcribing all interviews, the researcher randomly checked 1/3 of the 6 transcripts (i.e., 2 interview transcripts) to further ensure accuracy. Due to discrepancies found in both transcripts (i.e., incorrect words and/or phrases) the researcher further examined each interview transcript and made corrections as necessary.

The researcher requested that each interviewee prepare to review their individual transcript and provide comments/corrections as necessary to ensure the accuracy of the researcher's data collection. The interviewees provided feedback to the researcher regarding their summary of responses via email. One interviewee, however, could not be reached despite the researcher's attempts via email, phone, and standard mail. Therefore, no feedback was obtained regarding this participant's transcript. All downloaded/written information and interview transcripts were coded by number and stored in a locked file cabinet to protect each interviewee's confidentiality.

Bogdan and Biklen (1992) stated that a theme is a concept or theory that emerges

from the researcher's data. The researcher prepared for data analysis by creating coding categories to organize the transcript data into units, while specifically attending to words, phrases, patterns of behavior, participants' ways of thinking, and events that repeated and stood out (Bogdan & Biklen, 1992). Coding categories are developed to organize data formed from statements about specific settings, human patterns of behavior and ways of thinking, and/or situations. The coding categories help to identify information provided about pre-existing topics of concern (e.g., screening, referral, etc.), as well as new information gathered during the interview.

Analysis strategies outlined by Krueger and Casey (2000) were followed. Specifically, each transcript included the participant's number, the date, and page numbers to ensure that each segment of text could be verified. Although the data was naturally organized into categories due to the interview protocol used to obtain responses, the researcher kept one transcript in tact and the other transcript was used for organizing the data into thematic categories. Coding occurred through the use of multiple color-coded vertical lines drawn down the left margin of the paper which enabled the researcher to cut individual segments of text from its original transcript to create thematic categories. Using color codes also allowed for coding statements having one or more categories/themes. The researcher attached cut segments of text from transcripts onto large, individual sheets of paper which represented themes. Afterwards, the researcher wrote descriptive statements of each category which described what was reported by the participants. Additionally, the researcher presented a list of themes, descriptions, codes, and examples derived from the data to her methods committee member for final review.

For the purpose of this study, item-level analysis was used to answer the five research questions posited by this researcher, while pattern-level analysis described trends and linkages that were identified across participants relative to each research question (LeCompte & Schensul, 1999). Once inferences were developed, the researcher utilized an external auditor to verify whether these inferences were logical and grounded in findings (Brantlinger et al., 2005). This external auditor was a pediatrician who was not informed about this research study, yet was well versed in the literature and had a wealth of experience in working effectively with young children with developmental delays and disabilities. Feedback provided by the auditor was utilized to make revisions as necessary. At the culmination of this study's analysis, the results were shared with the participants via email.

Research Credibility

Throughout this study, the researcher employed several credibility measures to ensure that data collected were reliable and valid. Brantlinger et al. (2005) stated that these measures are commonly used to indicate that consumers can trust the research. See Table 3 for details on credibility measures chosen for this study.

Table 3. Credibility Measures

Credibility Measure	Rationale for Inclusion in Study
<u>Data Triangulation</u> - use of varied data sources	Multiple sources (participants) were interviewed to encourage robustness.
<u>Audit Trail</u> – tracking research process via logs providing information on the date, time, and length of interview, etc.	This process was used to document and substantiate that sufficient time was spent to claim dependable and confirmable results.
<u>Thick-detailed description</u> – reporting sufficient quotes from the participants	This process provided evidence for the researcher’s interpretations and conclusions.
<u>External Auditor</u> - using an outsider to the research to examine if, and confirm that, a researcher’s inferences are logical and grounded in findings	This process strengthened the research by providing confirming or disconfirming feedback to the researcher’s conclusions, which also added validity to the study.
<u>Integrity Check</u> – using the participants within the study to determine whether the information gathered via the interview transcripts is accurate	This process strengthened the research by determining the accuracy of the data collected and providing an opportunity for clarification.

Chapter Four

Results

The results of this study have been presented in terms of themes, AAP guidelines, and barriers to AAP guidelines that emerged from the analysis of participant interview transcripts. Data were analyzed relative to the American Academy of Pediatrics (AAP) framework regarding recommendations for overcoming barriers to providing quality services for young children with developmental needs (American Academy of Pediatrics, 2001a).

Pediatrician Demographics

One hundred and fifty pediatricians who also were members of the American Academy of Pediatrics (AAP) were contacted via email in an effort to encourage their participation in completing the online survey. A response rate of 19% was obtained as 28 pediatricians completed the online survey. Pediatricians who were generalists (n=17) and pediatric subspecialists (i.e., developmental pediatricians) (n=11) participated in completing the online survey.

Figure 1 reveals the percentage of 28 pediatricians by age range that completed the online survey. According to the results, the majority (i.e., 39%) of pediatricians who completed this survey were 43 through 53 years of age. Findings indicated by O'Connor, and Sharp (2000) via the American Academy of Pediatrics' Association for Health Services Research and Health Policy revealed the average age of pediatricians in 2000 as 43 years.

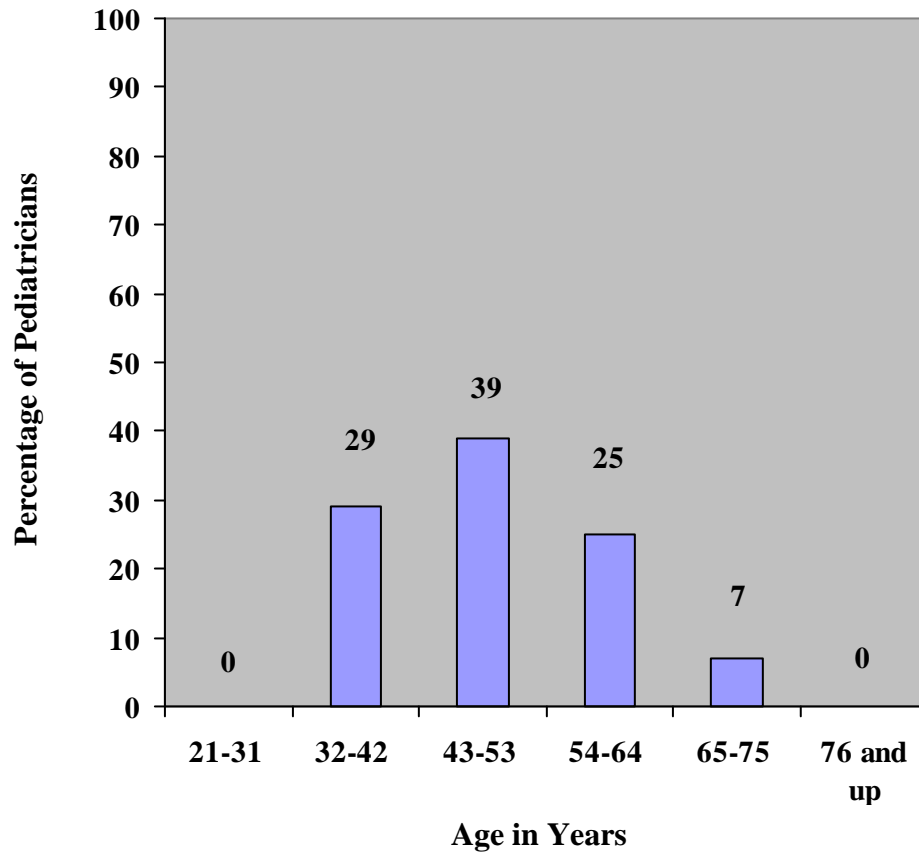


Figure 1. Survey Participant Demographics – Age

Figure 2 displays percentages for both male and female pediatricians who completed the online survey. The results of this study indicated a higher percentage of male (i.e., 54%) when compared to female (i.e., 46%) respondents. However, demographic data from 2006 showed a higher percentage of female (i.e., 53%) versus male (i.e., 47%) pediatricians.

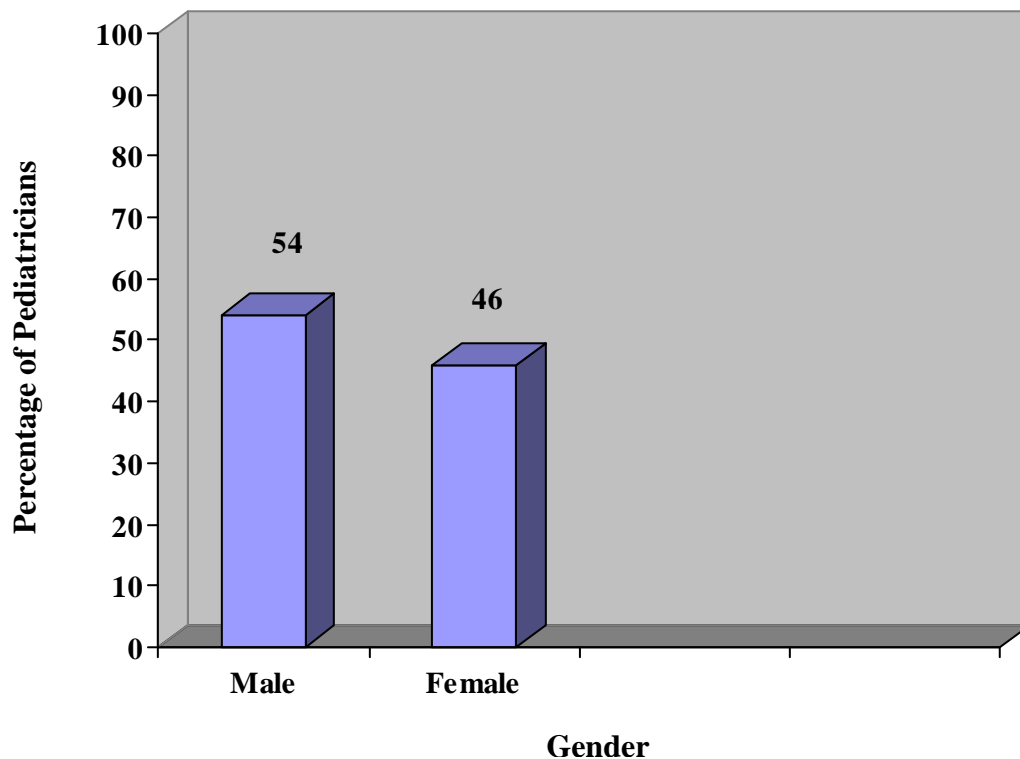


Figure 2. Survey Participant Demographics – Gender

Of those who completed the online survey, 61% (n=17) were general pediatricians and 39% (n= 11) were pediatric subspecialists. See Figure 3 for specific details.

Demographic data from the American Academy of Pediatrics (2001b) show a larger percent of time engaged in general pediatrics was reported by male (63%) and female (73%) pediatricians, when compared to males (37%) and females (27%) engaged in a subspecialty.

Additionally, this information can be compared to the data obtained on the online survey within this study. A further analysis of pediatrician and gender type showed a

higher percentage of general pediatricians who were male (25%) and female (36%) when compared to subspecialists who were male (28%) and female (3%).

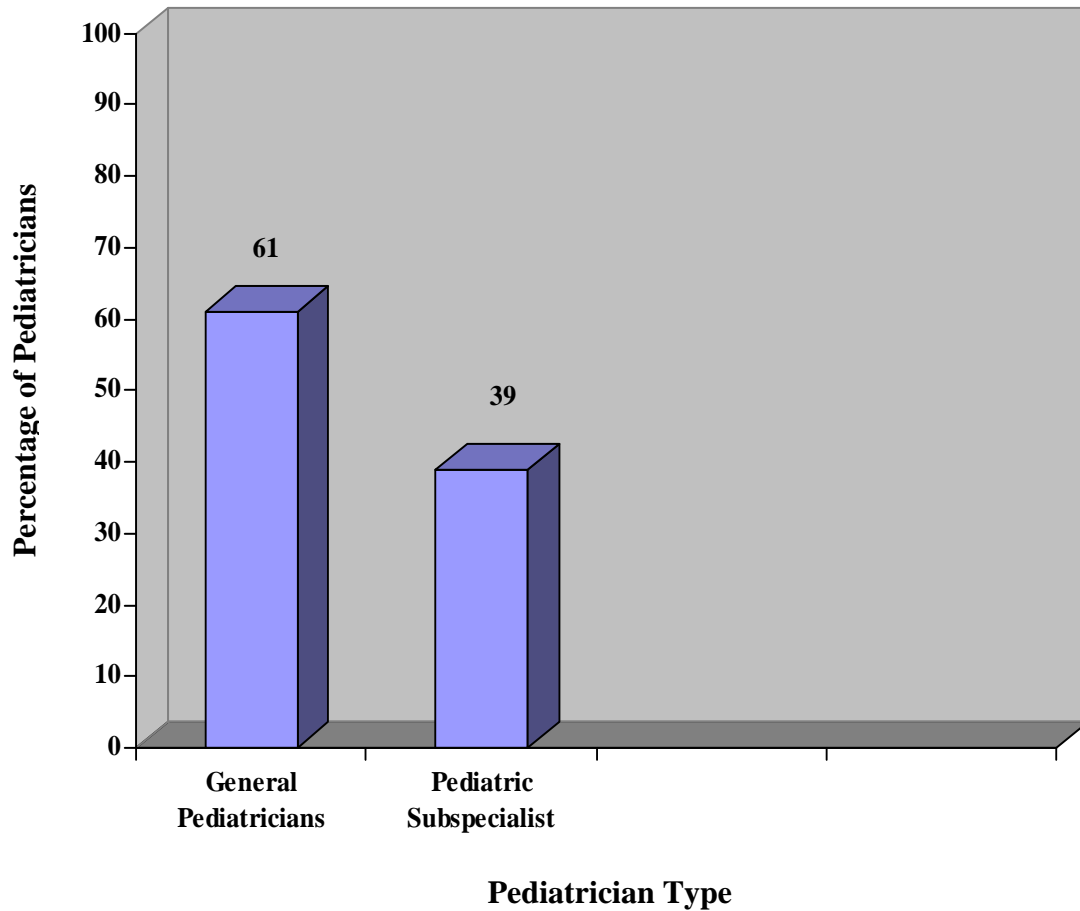


Figure 3. Survey Participant Demographics – Pediatrician Type

According to Figure 4, the highest percentage of pediatricians participating within this study has worked within the field for at least 20 years (i.e., 43%). This percentage was followed by 15 through 20 years of practice, one through five years of practice, ten through fifteen years of practice, and five through ten years of practice. Pediatricians who have been in the field for five years or less did not respond to the survey.

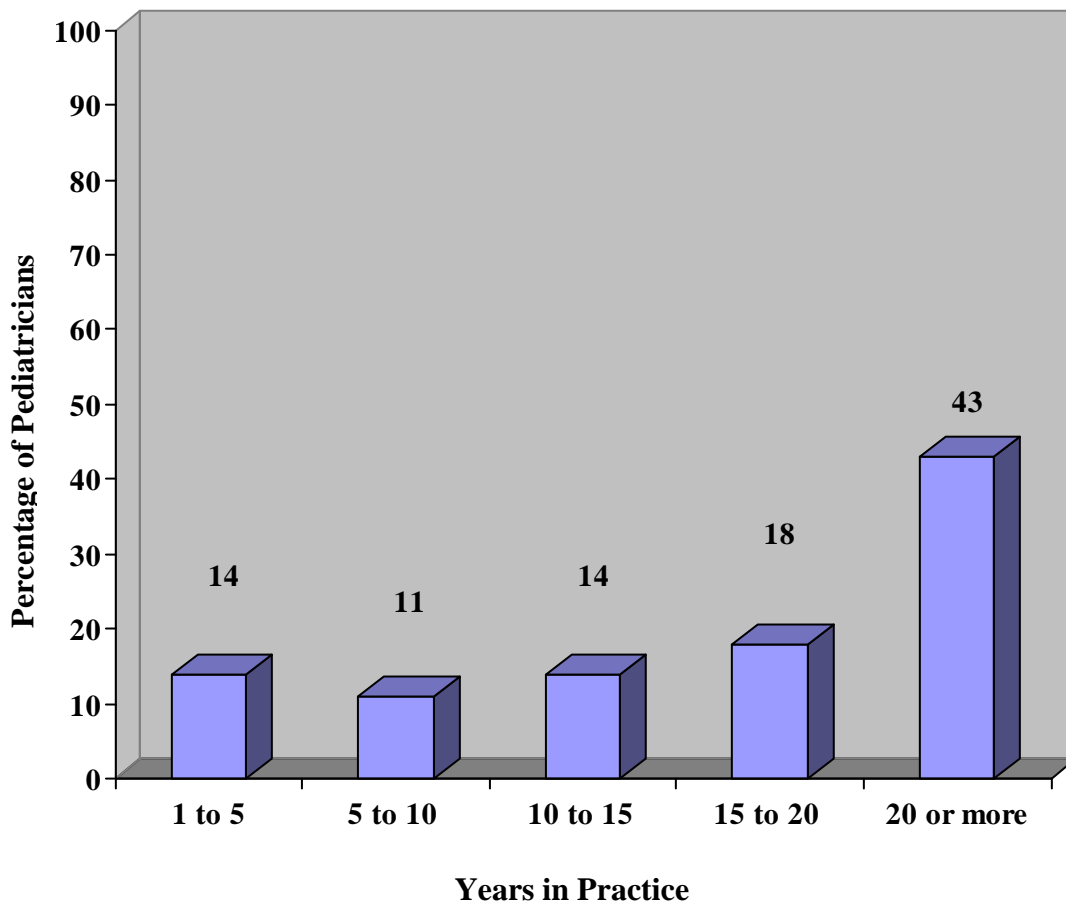


Figure 4. Survey Participant Demographics – Years in Practice

Figure 5 displays the percentage of pediatricians who worked in specific practice settings. The data shown indicate that approximately 40% of pediatricians classified their work setting as “other”. Examples of this setting are pediatric emergency department, residency program, and academic hospital. The private practice setting was the next highest percentage (25%), followed by the hospital (21%) and clinic settings (14%).

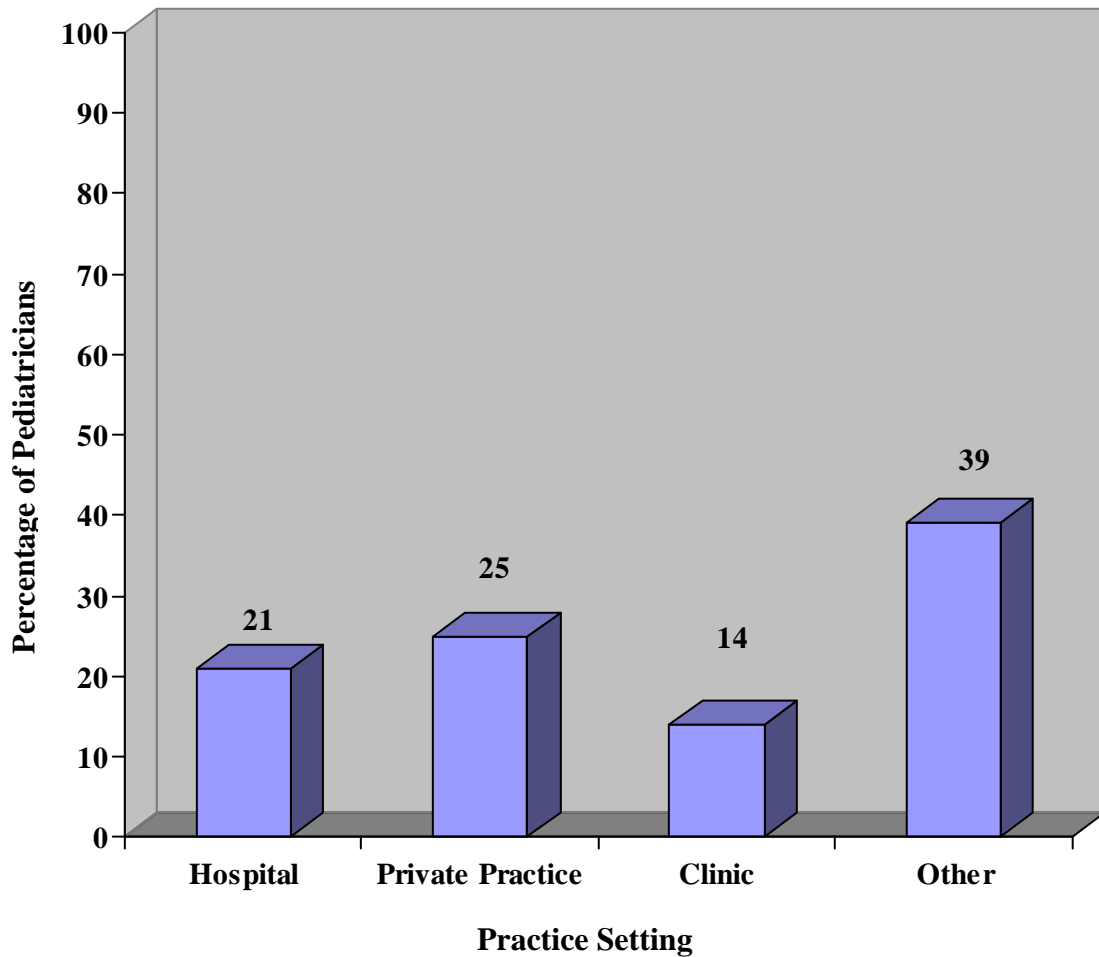


Figure 5. Survey Participant Demographics – Practice Setting

Figure 6 displays the percentage of pediatricians by location. The majority of pediatricians responding to the online survey reported practicing within urban areas (68%), followed by suburban areas (32%). Rural settings were not indicated by respondents as an area of practice. According to the American Academy of Pediatrics (2001b) demographic data, pediatricians typically worked in an urban location (i.e., 48% male; 51% female), followed by suburban (i.e., 37% male; 35% female), and rural (i.e., 15% male; 14% female) locations. A further analysis of demographic data obtained from

the online survey showed that 43% of male pediatricians and 25% of female pediatricians worked within urban locations. This information was compared to 11% of male pediatricians and 21% of female pediatricians who reported working in suburban locations.

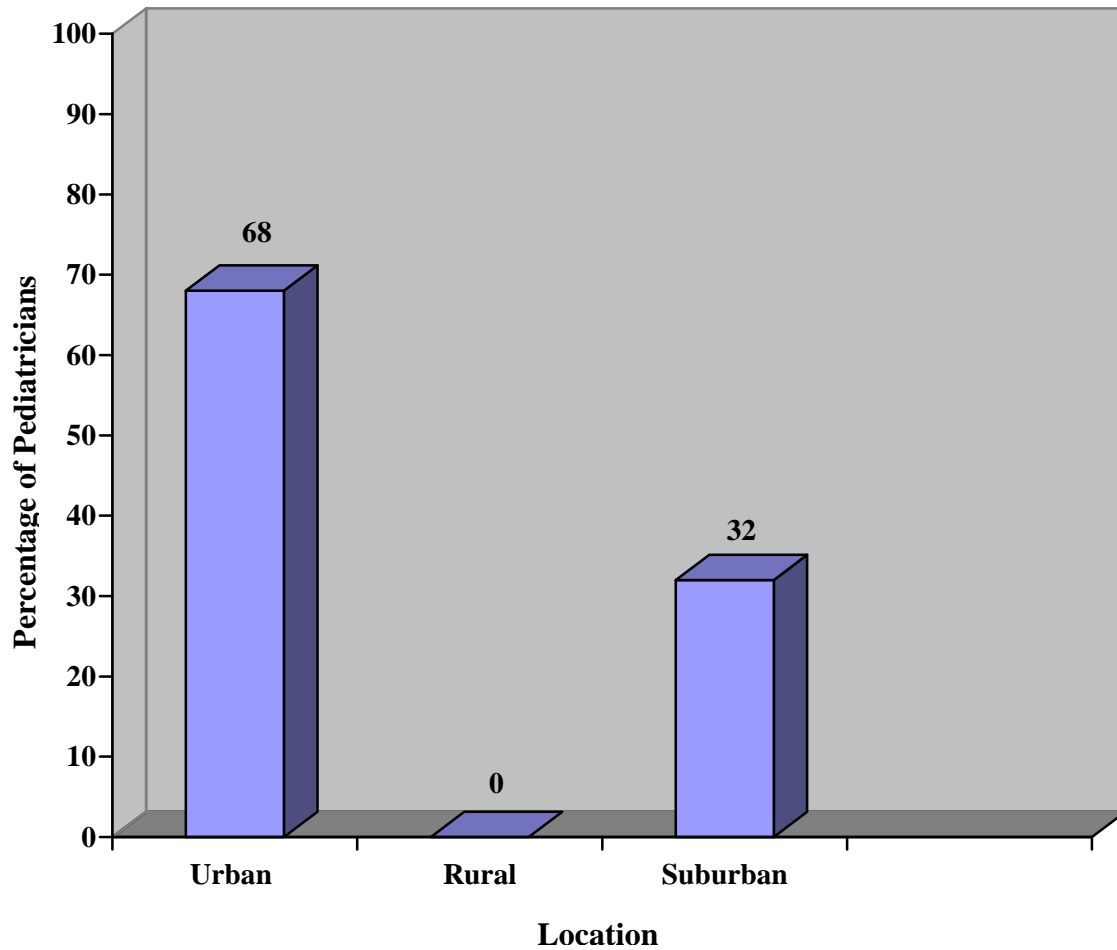


Figure 6. Survey Participant Demographics – Location

According to Figure 7, 25% of pediatricians participating in the online survey worked between 30 and 40 hours, 40 and 50 hours, and 60 and 70 hours per week. A smaller percentage of the sample (14%) worked 40 to 50 hours per week while 11% worked the most hours per week (i.e., at least 70 hours).

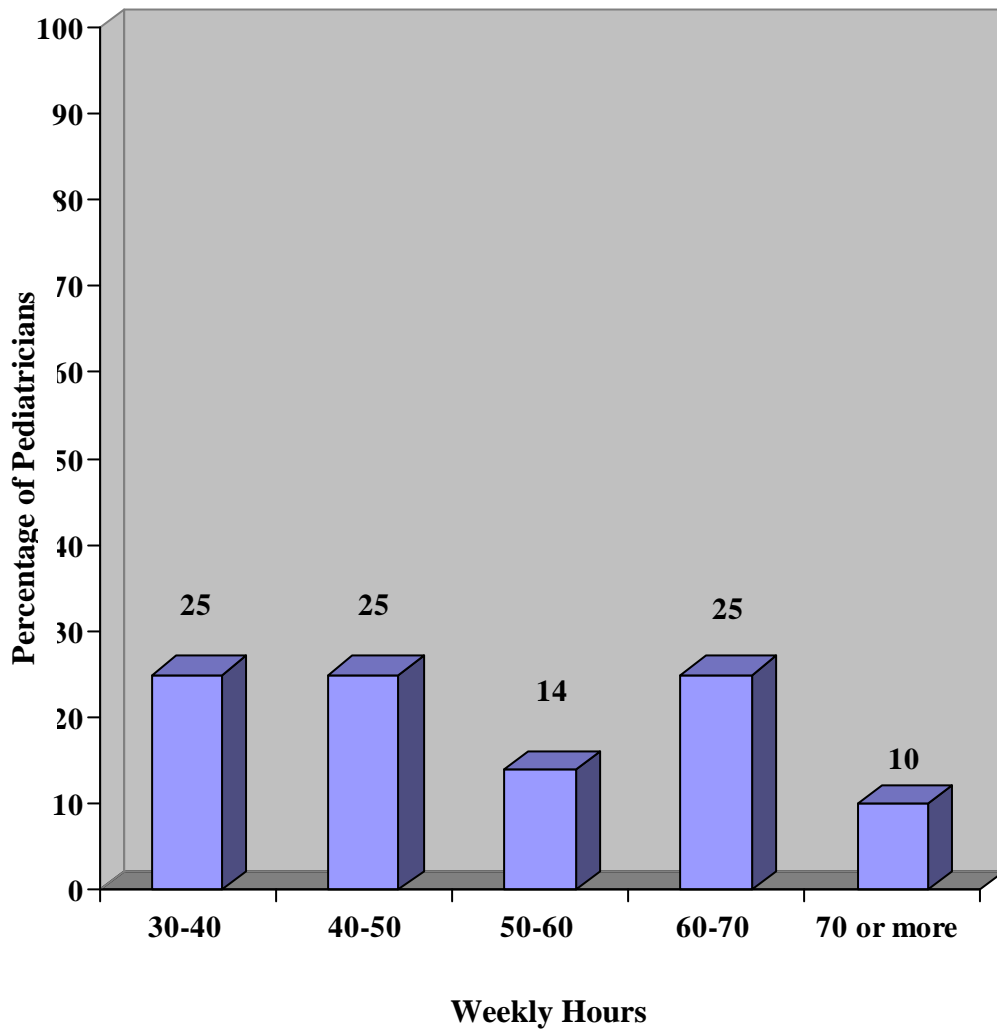


Figure 7. Survey Participant Demographics – Weekly Hours

Figure 8 demonstrates the percentage of time pediatricians reported engaging in eight of the nine AAP guidelines. According to the survey data, pediatricians reported that they most frequently (i.e., 80-100% of the time) refer children with delays in a timely manner, followed by increasing parent awareness of disabilities and resources,

interpreting consultant findings to assist families, maintaining relationships with community resources, presenting screening results to families using a culturally-sensitive/family-centered approach, determining the cause of delays or consulting with others, staying updated on child issues, and acquiring the skills needed to administer and interpret screeners. Furthermore, most pediatricians (35%) reported that they spend the least amount of time (1-20%) staying updated on issues (e.g., developmental, screening techniques, community resources, etc.). Additionally, presenting screening results to families using a culturally sensitive/family-centered approach, and acquiring the skills to administer and interpret screeners were reported as “not applicable” by the majority of pediatricians responding to the online survey. See Figure 8 for specific percentages regarding each AAP guideline.

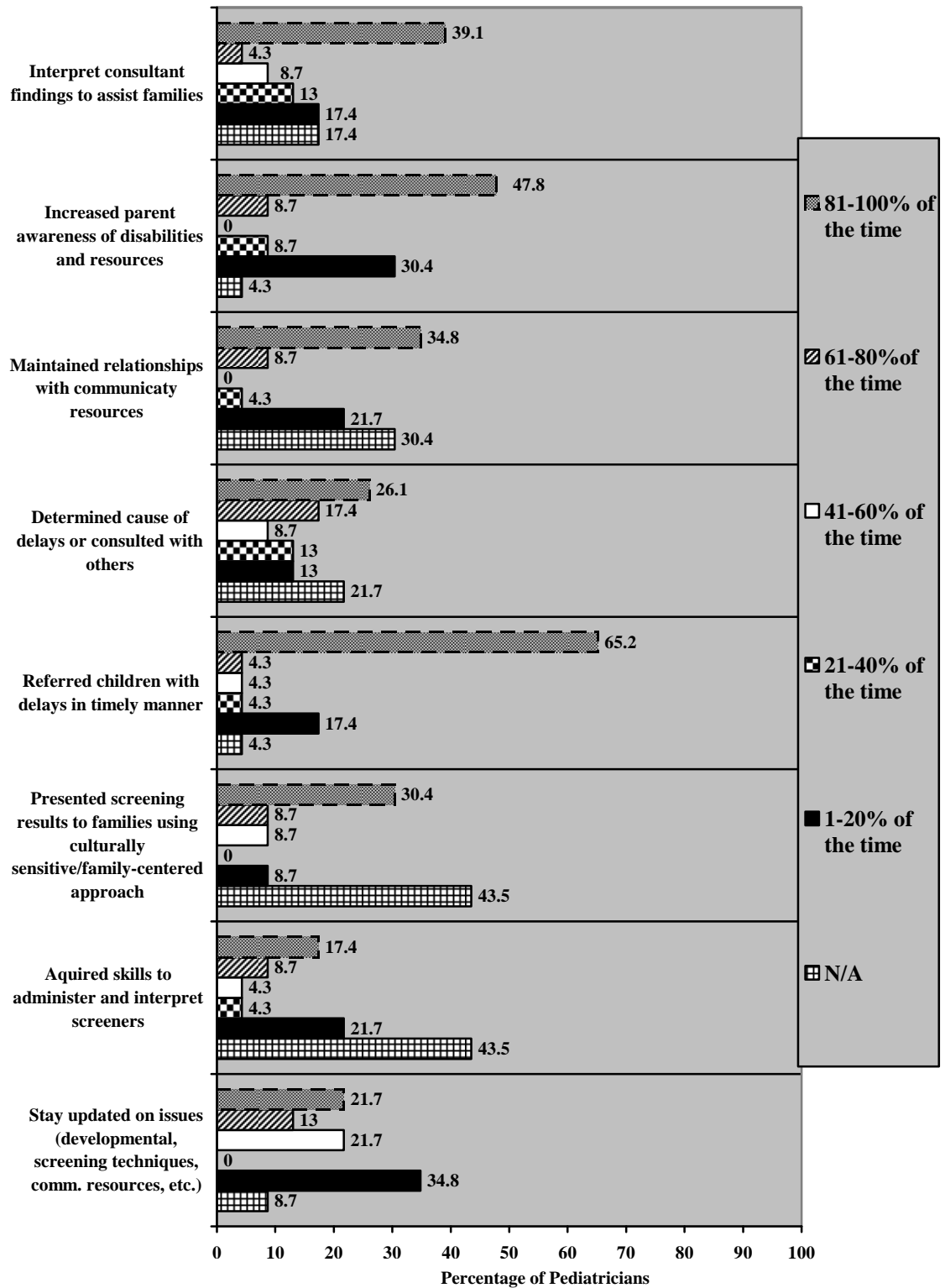


Figure 8. 28 Survey Participants – Percentage of Time Engaged in Each AAP

Figure 9 illustrates responses provided for the final AAP guideline inquiring about whether pediatricians have developed a strategy for providing periodic screening within the context of office-based primary care. Ten pediatricians (36 %) responded “yes” 13 pediatricians (47 %) responded “no” and 5 pediatricians (17 %) did not provide an answer for this question.

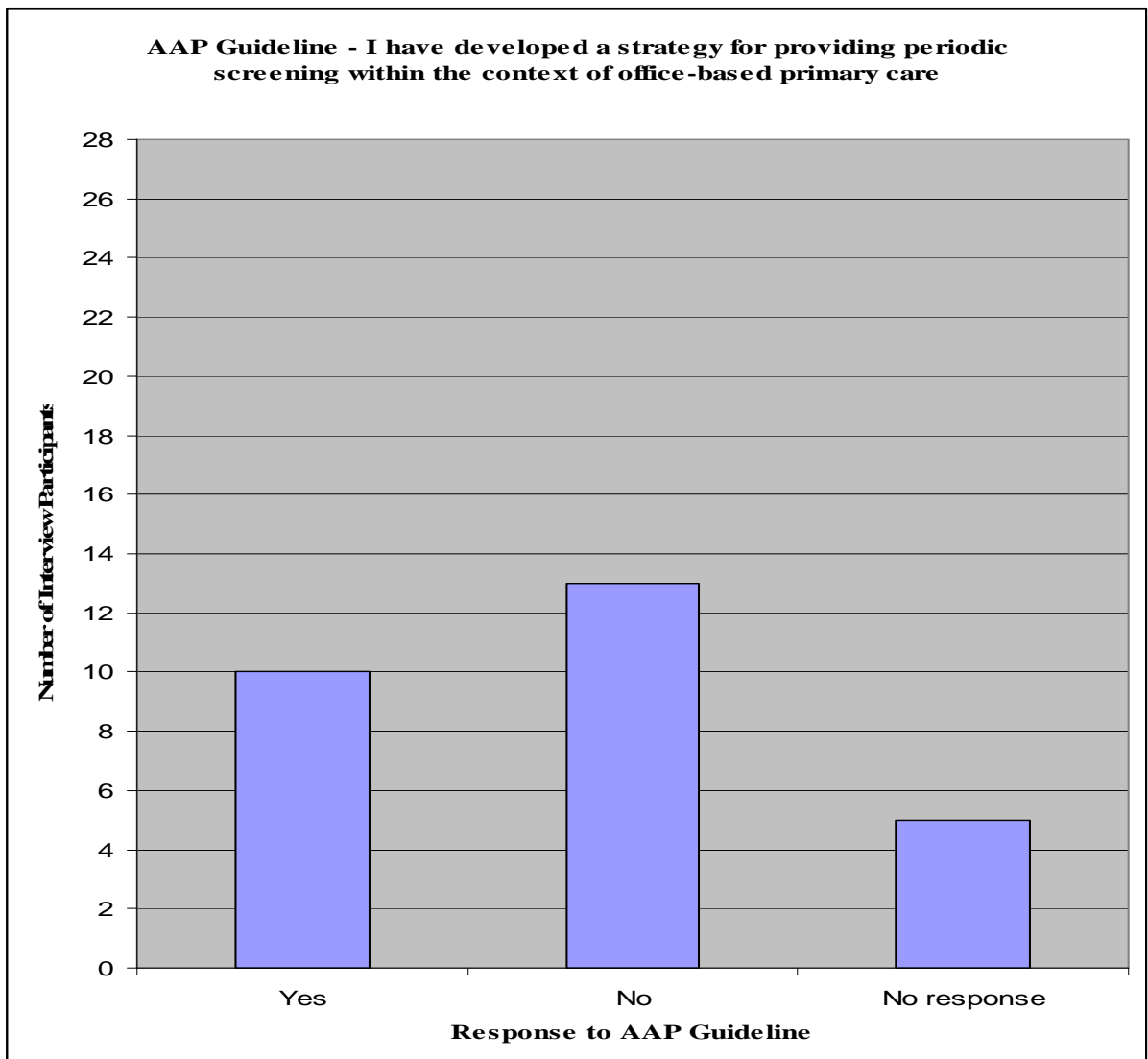


Figure 9. 28 Survey Participants – AAP Guideline: Providing a Strategy for Periodic Screening

Interview Participants

Due to this study's focus on generalists, a total of six general pediatricians (out of 11 who responded to the online survey) within the West Central Florida area were selected to participate in a semi-structured interview. Six generalists were rank ordered by the number of AAP recommendations implemented. The percentage of time spent engaging in each recommendation was considered only in the event that general pediatricians reported implementing the same number of AAP recommendations. This occurred with two general pediatricians who reported engaging in eight AAP recommendations. One of these potential participants was unable to attend an interview with the researcher. Consequently, the researcher contacted the general pediatrician who was next on the list of rank-ordered survey respondents.

The researcher attempted to schedule each participant's interview by the number of AAP guidelines reported, although this did not occur with the two participants. Specifically, a general pediatrician who reported following four AAP guidelines was interviewed prior to another general pediatrician who reported following five AAP guidelines. This occurred due to scheduling conflicts with the final participant. Additionally, each general pediatrician participated in a face-to-face interview with the exception of the final participant who preferred to conduct a phone interview due to difficulties meeting face-to-face. Interview time frames ranged from 45 minutes to one hour and thirty minutes. See the Audit Trail in Appendix H for additional information on interview dates and time frames.

Purposive sampling and demographic variation were utilized to select a participant sample that had experience with implementing AAP best practices, practiced

in a variety of settings, represented both genders and a variety of age ranges, and represented a range of years of experience within the field of general pediatrics. Table 4 provides descriptive information for the six general pediatricians who participated within the interview portion of this study. These data indicate that the majority of interview participants were within the 32-42 age range (50%), were female (67%), had practiced for 10-15 years (50%), currently work within clinic settings (50%), and work between 40 and 50 hours per week (50%). An equal percentage of general pediatricians worked within both urban (50%) and suburban (50%) areas.

Table 4. Participant Demographics – 6 General Pediatricians

Interview Participant	Age Range	Gender	Years in Practice	Practice Setting/ Location	# of hours worked per week
One	32-42	Male	10-15 years	Academic (and Clinic Setting) /Suburban	40-50
Two	32-42	Female	10-15 years	University Affiliated Clinic/Urban	40-50
Three	43-53	Female	20 years or more	Private Practice/Urban	30-40
Four	65-75	Male	20 years or more	Private Practice/Suburban	30-40
Five	32-42	Female	5-10 years	Clinic/Suburban	40-50
Six	43-53	Female	10-15 years	Hospital/Urban	50-60

Table 5 denotes the number of general pediatricians (out of six participants) who reported engaging in each AAP guideline. The ratios ranged from 3 out of 6 (i.e., 50%) to 6 out of 6 (i.e., 100%). See Table 5 for further details.

Table 5. Ratios of 6 General Pediatricians Reporting the Facilitation of AAP Guidelines

9 AAP Guidelines	Ratio of 6 General Pediatricians-Online Survey	Ratio of 6 General Pediatricians-Interview
Maintain educated about developmental issues, risk factors, screening techniques, and community resources to assist with consultation, referral, and intervention.	6 out of 6	6 out of 6
Acquire the skills needed to administer and interpret valid and reliable developmental screeners.	3 out of 6	3 out of 6
Present screening results to families using a culturally sensitive and family-centered approach.	4 out of 6	6 out of 6
Refer children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community.	6 out of 6	6 out of 6
Determine the cause of delays or consult with the appropriate consultant for determination.	5 out of 6	6 out of 6
Maintain relationships with community-based resources <u>and</u> coordinate care with them through the medical home.	4 out of 6	0 out of 6
Increase parents' awareness of developmental disabilities and resources for intervention.	6 out of 6	6 out of 6
Be available to families to interpret consultants' findings.	5 out of 6	5 out of 6
Develop a strategy for providing periodic screening in the context of office-based primary care.	3 out of 6	3 out of 6

AAP Guidelines – Interview Findings

Using the framework provided by the AAP, nine guidelines have been identified for the developmental screening and surveillance of infants and young children. Within this research, themes and patterns developed regarding general pediatrician's implementation of these AAP guidelines. Specific quotes are provided to facilitate further understanding of how general pediatricians have implemented these guidelines within their respective work settings.

The following sections are organized by themes to best represent the findings from this study. The specific themes include training and continuing education, learning about developmental screeners, using a culturally-sensitive/family-centered approach, parent awareness, referring children with delays and disabilities, determining the cause of delays and disabilities, connecting with community resources, barriers to implementing AAP guidelines, and overcoming the barriers to AAP guidelines. The researcher provided thick-detailed descriptions as a credibility measure to report sufficient quotes from each participant.

Training and continuing education. The interview began with a discussion concerning the methods by which general pediatricians remain educated about various early childhood issues. This inquiry probed areas such as child development and risk factors, screening techniques, and community resources. General pediatricians within this study provided several practical methods that they have and continue to use in order to increase their knowledge base within the aforementioned areas. For example, residency training, although a previous experience, was often noted. More current methods include the reading of print and electronic sources (i.e., print brochures, websites, journals,

magazines, and email correspondence). Print and electronic sources were most frequently mentioned by 100% of the participants interviewed. Listening to lectures via audio digests and while attending meetings, in addition to consulting with colleagues also were reported as learning tools. Participants One through Six each provided responses pertaining to their knowledge of child development, risk factors, and screening techniques.

Participant One stated the following:

I have a special interest in children with special needs so I have...in national meetings...C.M.E.s. I might attend some of the workshops and lectures related to special needs like ADHD, children with disabilities, and stuff like that. As far as resources, the other resources would be through the AAP. It's more like, it's the kind of information that I don't seek out - it finds me. For example, I am a member of the Council on Children with Disabilities with the AAP, so I'm on their listserv. So I might not go into depth on everything they send, but sometimes they send a listserv which might talk about a certain guideline. And if it's something of interest, I might look more into it. Otherwise, I might just scan it. So, the listserv might be helpful as you can pick and choose what you would like to go more deep into.

Participant Two stated the following:

Usually through reading *Pediatrics* or the developmental people will send us little brief summaries of what's going on with either the AAP recommendations or...that's mostly it...Usually it's just email or summaries of the latest AAP recommendations.

Participant Three stated the following:

I not only read medical magazines, but sometimes you learn even more from the lay press than in medical magazines because some medical people are in “Mecca” and they are totally disconnected from reality.

Participant Four stated the following:

By articles, reading periodicals and journals, *American Academy of Pediatrics*, *Pediatrics in Review*, and other pediatric journals.

Participant Five stated the following:

Usually, I use *Pediatrics in Review* which is a journal that I get once a month. I’ll not read it in depth, but I’ll thumb through to see what catches my interest...

That’s the biggest. I get some AAP emails from time to time that send me to links on the AAP site.

Participant Six stated the following:

I attend conferences, read articles, and attend Grand Rounds.

Continuing education – community resources. General pediatricians within this study provided methods by which they stay educated about resources for children and families located within the community. Participants Three, Four, Five, and Six reported that they stay educated about community resources by either networking or consulting with other professionals. Staff members (e.g., nurse, social worker, etc.) were also described as taking responsibility for gathering information. Also, one general pediatrician reported that she has received brochures from community resources in her area.

Participant Three stated the following:

That one is a little bit harder. Usually, I learn about community programs through the mail...I receive a lot of cards that we are...we have compiled a list of psychologists and mental health counselors that we like or that accept insurance. We had a nurse here whose child had severe psychiatric problems and she took special interest in finding out resources that were available and that was her cup of tea...to do all this stuff. So we have that.

Participant Four stated the following:

We have several pediatricians in our group. We talk with each other and we have meetings. I'll say, "I've run into this problem...have you run into that yet?" and they'll say, "Yeah, I've found this source was good." Other pediatricians in the community and in our group are helpful with that.

Participant Five stated the following:

I don't know if I stay as up-to-date as I indicated on the survey. I get the brochures that they send from EIP...HOT DOCs is one of them.

Participant Six stated the following:

We have resources in the hospital such as a social worker.

Participants One and Two expressed difficulty when asked about their ability to stay up-to-date regarding community resources available to young children. Although Participant Three provided methods by which she engages in the guideline, she also described engaging in this recommendation as her "weakest point".

Participant One stated the following:

Local resources sometimes are very hard. I find it challenging to know what resources are out there.

Participant Two stated the following:

For the community resources, usually we find out more of those on our own.

Participant Three stated the following:

I would say that's my weakest point. It's very hard to keep up with the community resources but unfortunately there are not too many good community resources unless you have money. That's the reality of life. Unless you have money, the resources are terrible.

Learning about and using developmental screeners. During the interview, general pediatricians were asked the manner by which they have acquired skills to administer and interpret valid and reliable developmental screeners. They also were queried regarding their ability to develop a strategy for providing periodic screening in the context of office-based primary care. Participants One, Two, and Three each provided information supporting these two themes. Specifically, Participants One and Two noted their residency training as one source, in addition to attending lectures. Participant Three reported that she often reviews periodicals (e.g., *Pediatric News*) and has researched free screening tools from the internet that she has incorporated into her practice. Furthermore, Participants One, Two, and Three discussed using valid developmental screeners within their respective settings.

Participant One stated the following:

...we administer the Ages and Stages questionnaires. We administer some of the

developmental questions based on the Denver screening. So, those were acquired during residency. We used to use the Denver at that time and now the Ages and Stages became more popular – it's easier.

Participant Two stated the following:

The primary one we use, well, we've taken the Denver which we've been trained on and we've abstracted some of the major questions from it and that's what we have on our normal well child visit checks that we show residents...so we've learned how to use the Denver...and the Ages and Stages questionnaire. Those are the two main ones we use for screening.

The ASQ was actually, [doctor] taught us how to use it...and lectures also...She was actually doing a research study bringing the ASQ into different clinics to see if we could improve the amount of screening being done by the residents. So, she taught the residents and us through lectures, how to administer the ASQ and how to score it.

Participant Three stated the following:

Yes, let me show you what I use. This is *Pediatric News*, a newspaper published by the American Academy of Pediatrics that keeps me updated with pediatric news. Sometimes I read articles that are very helpful and I save them. For example, this article from last year discussed how to screen specifically for Autism and depression and directed us to a web site (brightfuture.org) which these forms could be downloaded for free and used in the practice. I immediately implemented those forms and started using day to day. I downloaded the M-CHAT (a screening tool for the detection of early autism), BECK (a screening

tool for depression) and this PEDIATRIC INTAKE FORM that I found extremely helpful during my initial intake of a patient with behavioral or academic problems.

Participants Four and Five did not mention the methods by which they learned to use screening tools. Additionally, both participants stated that they either prefer not to use screening tools or have chosen not to incorporate these tools into the office visit due to time and staff constraints. Additionally, Participant Six reported that she does not use developmental screeners as part of her role within the hospital setting.

Participant Four stated the following:

I don't use a lot of screening techniques. I have not been one that uses those. I have not found them very helpful.

They're time consuming and I don't have a lot of time to do them, and when I'm through, I'm not sure what I've accomplished other than what I see when I examined the patient and talked to the mom. I used to use it when I first started. I really didn't find them that useful. I just went on clinical evaluation because they really didn't add much.

Participant Five stated the following:

We've tried to do it here and we elected not to. It's kind of a unique situation where it's like I was with my partner and we work exclusively with medical students...seeing patients and then making sure their work is correct and they're generally much slower. So, it wasn't a feasible situation to turn over the rooms quick enough.

... I have one nurse to do everything. So, I can't even ask her to do that.

Participant Six stated the following:

I'm an in-patient doctor. Pediatricians refer to me. I see maybe, at most, twenty patients a day which is eighty to one hundred patients per week. I am a Pediatric Hospitalist. Children don't come to us for developmental issues. They typically come for something else.

Determining the cause of delays and disabilities. General pediatricians within this study indicated the methods they use in an effort to determine the causes of delays and disabilities. As previously mentioned, general pediatricians engage in a series of activities, known as developmental surveillance, which assist them in understanding the nature of a child's developmental concerns. Some of the activities include, but are not limited to, engaging in periodic screening by using questionnaires and completing observations over time. The data also indicated that when general pediatricians are in need of assistance to determine a child's concerns, consultation then takes place. Each of the six general pediatricians reported consulting with other professionals. Specifically, they reported consulting with some individuals to determine the cause of delays, and others to obtain additional information regarding a child's functioning. General pediatricians mentioned consulting with developmental pediatricians, specialists (e.g., neurologists), teachers, school nurses, social workers, and/or school psychologists. However, the most contact was noted among health professionals and teachers.

Participant One stated the following:

Sure, I think for the most part, as long as I don't think the delay is something coming because of prematurity or being a normal type of...well, usually a delay is not normal but if the child is otherwise normal and has been gaining milestones,

but for one reason or another they're a little bit behind but actually making headway and I found a reason like maybe mom was not paying attention to him or he is with the babysitter and he's left oftentimes laying down so he doesn't really get enough motor stimulation or something to fix, then I might not consult initially with someone. I might try some of the suggestions that I talked about, like giving her handouts or examples of some things to do. Now, if she tried that and it didn't work, or the child has other, maybe neurological problems like the physical exam is abnormal, the kid's not cognitively appropriate, it looks like he may be a little retarded or looks like the child has some syndrome, all of those we definitely have referred most of the time. I even would refer to development like [doctor] for more of the normal stuff. But when it becomes abnormal, we require more than just [doctor]. Like maybe neurology or genetics or other specialists to be involved. So, sometimes mostly I guess we're going back to how severe the delay is to determine going to a specialist and whether there are any associated abnormalities that could be contributing to the delay. So the delay is there but is everything else normal or are there other neurological problems, genetics, or dysmorphic problems?

When asked whether he typically consults with others or simply refers patients on to the resource, Participant One remarked:

Most of the time we refer so we can allow them to manage at the same time. But, we are still their primary, so most of these consultants we refer to keep us informed by sending us copies of the visit. Some of them especially in the case of neurological problems, they need more than a one time visit and most of the time

it may not be fixed. They may be started on some seizure medication or something. For those, we usually want the neurologist to keep monitoring, or the psychiatrist, especially if medication.

The researcher further asked if he has ever consulted with individuals within the school system on the behalf of a child. Participant One replied:

Yeah, the only thing I can think of is more for ADHD or more for, if we're trying to advocate for a child to get tested through the school system for a disability more than like developmental delays. It's more for behavior or stuff like that. ...If we think that maybe there are some modifications that the school or teacher could do, or sometimes we get a note from the teacher that says that this kid needs to be tested or whatever...The teacher would send a note with the parent... So we call back to say, "What do you mean, give us an example" because sometimes some modifications for some ADHD kids, like putting them in front of the classroom to keep their attention, you know, things like that we may request that the teacher do. The other thing, for testing, if the child needs to be tested and the delay is long, sometimes I might get the social worker...our social worker is really good. He even goes to the school and a couple of times he even stays in the class to see what...like if it was disruptive behavior...he would watch what happens to help the family and teachers.

Participant Two stated the following:

Some of them are relatively straightforward and others, if they're premature, they're at a much higher risk for developmental delay. If they have a chromosomal abnormality, like Down's Syndrome or another more obvious where

you can look at them and go “Oh yeah, they’ve got X chromosomal problem, etc. then it makes it pretty easy to determine their cause. If they don’t have an obvious cause, sometimes we do some bloodwork looking for a chromosome abnormality. We may send them to genetics to look for a chromosomal problem.

...If there’s no cause and they look like a healthy, normal child but you can tell there’s a developmental delay anyway, then we may send them to a developmental pediatrician like [doctor] to try and figure out better what’s causing their delays. Sometimes we don’t know a true source...there’s no cause that we know. But they’re still delayed so they still need services either way.

Participant Three stated the following:

Oh, I know my limits. I know that if I have a child with an antisocial personality, I can’t handle that...or a child that’s depressed. Or, if I try to treat someone with ADD and it doesn’t work...manic depression, bipolar disorders, the ones that just blow a fuse...I cannot do it. You have to go a psychiatrist.

When asked if she has ever worked with school personnel in addition to teachers,

Participant Three responded with the following:

Well, they send me those forms and if they write down...and sometimes it’s a big “if I have time”...if they write down “please feel free to contact”, sometimes I do. That’s especially if the child’s not doing well. But, we do not have the time or the resources. I don’t have anybody I can pay to call and see how they are doing in school...and I cannot charge for services like that. So I am limited financially. Now if they call me, I always return their call.

The researcher further asked if anyone from the school system has ever sought her for consultation, Participant Three replied:

School psychologists. There was a particularly good school psychologist who used to call me to tell me that a medication was not working or that the child was having other problems. She was very good. She left that school and I haven't heard from the new one. In my fourteen years in practice, maybe two or three guidance counselors and school psychologists have reached out to me, but very few...It's one thing when the parents tell you and another thing when you know what's really going on.

Participant Four stated the following:

I send them to the neurologist because for many of the developmental problems, there is no etiology that we can put our finger on for many of them. After we do a routine workup, we don't find a reason. It's hard to put your finger on what the problem is. There's one family that has a child that I'm thinking of now that we've sent to numerous places all over the country and has a marked developmental delay. Nobody's been able to put a name on it and there's been an unknown etiology. He's seen world-class neurologists and geneticists and he's been treated at the USF program. Some of them you just can't find out.

Participant Four also was asked if he has consulted with individuals within the school system or vice versa. He responded:

With the school system, it's more of them through the parents really. My contact with the school system is mostly with kids having ADHD, which I have decided that I don't do. It's a very complex problem and I have just gotten out of doing

ADD. But when I was doing that, they were contacting me through the parents indirectly, trying to get the kid on medication. It could be the teacher or the school psychologist who thought the kid needed to be on medication. Frankly, feel that a lot of kids are labeled ADHD and put on medication when they shouldn't be on medication.

...Most of the kids are behavior problems in school so they want to calm them down so that they are not disrupting in school. That seems to be their goal. That's how it comes across. As long as a kid doesn't cause trouble in the classroom...that's our main goal. And the parents just want the problem to go away. Give the child a pill and make the problem go away and they don't want to do all the other things that are required. You know, you've got to make sure that the child gets their homework done every night. You've got to make sure that the child is taking his medication...parents...many of them just want the easy solution.

Participant Five stated the following:

Time and accessibility are issues. Other professionals are really hard to get a hold of. I don't blame her, that's just how it is. She's really the one person that I know I can get a hold of.

The researcher asked who Participant Five was making reference to and she replied:

[Developmental pediatrician.] She's really the only one that I know. There is another one who deals with autism, but I can't remember his name. His program is entirely pay upfront...no insurance. So, none of my patients can really afford it.

It's like five hundred something dollars for the initial assessment.

Participant Six stated the following:

This doesn't really happen in this setting. A time crunch makes it difficult to do this because there's difficulty reaching the patients' doctors.

Further probing regarding consultation within the school system generated the following response:

I've consulted with teachers and school nurses at times regarding children.

Referring children with delays and disabilities. In an effort to transition families from the assessment stage to referral stage, each of the six general pediatricians reported that their referral options (e.g., specific community resources), first, are based on the age of the child and type of concern. Second, parents are provided with resources that they can follow up with themselves. However, in cases where the child is in need of immediate intervention and/or the parents are experiencing challenges with scheduling an appointment date, the general pediatricians within this study often interject in an effort to expedite the referral process. Examples include making follow-up calls to the referred agency, writing a prescription for testing, referring to another resource (e.g., school age clinic) if services cannot be provided quickly by the referred agency, and utilizing the resources of a site-based social worker to assist with expediting the process.

Participant One stated the following:

Now, if at any point they need a referral for one reason or another, if they have developmental problems, usually the referral will happen that day. They [parents] get the referral, and it also depends on the age. If they are less than three years old, then they qualify to go to the Early Steps at least 1 visit – the initial visit. So,

we write the referral and the parents bring it to the front desk. At the front desk based on, I think, if they are less than two years old they actually send them to Early Steps. If they are older, then it becomes based on, if we're not doing it through the school, Speech or PT or something like that, then we would work through their insurance and see if, for example, they have Medicaid, where would they go. They would give them a list or a phone number to call. Occasionally, we have pressing time where you want this kid seen...it's the first time we've seen them, they are really behind, and they can't afford to wait another three months for an appointment. Then we might end up making a phone call for them and we've tried to get our social workers to facilitate that.

...Now if they have more global delays, like if the physical exam is abnormal, they may actually qualify for CMS – Children's Medical Services – because if they have cerebral palsy, for example, then we would actually use the social worker to get that done through the CMS system and get a caseworker who would actually help the family. Most of the time, those kids will need more than one referral. They would need to see neurology, and other people, so the CMS worker would help them through that.

Participant Two stated the following:

Usually we've got an order for developmental clinic or Child Find or Early Steps, or something like that. The only other way we'll sometimes do it is if they're a little bit older, we'll write an order for the school to do testing. But, I'm sure for the people who do that, there's tons of kids and it takes a long time and the squeaky parent gets the testing first. So, there's a lot of our kids who just kind of

fall through the cracks because the parents are unable to do it for whatever reason.
The school is too overwhelmed so it's six months or later.

Participant Three stated the following:

As I said, I use all the screening techniques and I use my questionnaires and before you leave I'll give you one. When I use those questions and I feel it's something I cannot handle, I give them my list. Say I have a doctor or psychologist here who takes most insurance and he's pretty good. I can send a lot of patients to him and he can screen them and I know about FDLRS for children with Speech impairments and I refer them there. I refer a lot of kids for physical therapy for fine motor concerns.

Participant Four stated the following:

Ok. There's a problem and if the child is under three, most of the time we send him to the early developmental program. That's a good resource for me. We start there. If they're over three, then we have to do it more because at USF they'll see the child and then refer to areas of other needs. Frequently, they'll need to see the Endocrinologist, Neurologist, and Geneticist. They have all of those there at USF so they can serve as the center and refer out and then I have to do that here over three and Child Find is a good place to start. They'll do hearing, vision, and developmental assessment and then if they're specific problems like neurological problems, I have various neurologists that I refer to. USF clinic does under three year old referrals. They're so good at doing it, unless that parent requests that I do it.

Participant Five stated the following:

Well, we assess them at every well-child check and we just have a few questions, four or five, within the developmental area...the social, fine motor, gross motor, language, and there's just a few screening questions that we do. Also, I ask if there are any parental concerns as well. If there are a couple areas that look like there are some issues on the developmental screen as part of the well-child check, or if there are some parental concerns that I see, I usually refer pretty immediately because I think it's a little difficult for my patients to get in because there's so many patients and not so many doctors in this area.

That's it for the zero to three. If they're older than three and not in kindergarten, then I use the FDLRS program. When they're in school, it's the school.

Participant Six stated the following:

...depending on the level of disability or developmental delay, we'll refer them to say, Early Steps, so they can get the intake here in the hospital and be sent out for outpatient work.

...If any concerns are found, we refer immediately to different resources as needed such as parent programs, neurology, Early Steps and FDLRS are good resources...speech therapists and genetics as well.

Using a culturally-sensitive/family-centered approach. The interview participants were queried concerning the manner by which they interact with families and provide results using a culturally-sensitive and family-centered approach. Once asked this question during the interview, three participants (i.e., those who answered this question negatively on the online survey) stated that they were unfamiliar with the definition of

these concepts. After providing follow-up probes (See Appendix E), however, it was found that each of the six general pediatricians indicated strategies they use to facilitate this AAP guideline. Examples provided by general pediatricians included the modeling of strategies, utilizing translators and other translation services, drawing concepts, providing brochures in the parent's native language, and holding informal discussions in an effort to learn about one's culture and/or to present verbal information in a simplified manner.

Participant One stated the following:

Depending on if they're Spanish, usually the residents have one-half day a week in clinic. So, what we try to do is have at least everyday one resident who speaks Spanish so there is somebody there that speaks Spanish. Now if it's something totally...like Japanese or whatever, sometimes we've used staff if there's anybody who speaks those languages. We've also used AT&T translation on the phone. That's usually it. We have some Creole and mostly Hispanic.

Participant Two stated the following:

We do have a lot of bilingual families and we have Spanish-speaking staff who translates for us. We have a Creole-speaking person but the other languages we have more trouble with. So if they're bilingual and we're not sure, that usually comes up more with the communication issues. They're going to be bilingual later and therefore they're delayed and there's some controversy about that so we try to get them to a bilingual speech therapist or someone who can assess at least in their native language are they ok or not. For the less educated, we try to explain it in as basic language as we can.

Participant Three stated the following:

I try to be sensitive with anybody. Well, I'm Spanish so if it's a Spanish family, I'm speaking Spanish. I try to learn the background of my patients as much as I can...where they are from, etc. We have a lot of Bosnians. They come here and they are Muslim. For example, if their belief is that the girls are inferior, I will not go for that. I will try to present it in a sensitive way, but I do not know how to answer that question.

...I have a father with a very low IQ and he's really trying hard. I talk to him and I let him know that this person is taking advantage of him and that he should do this, but there's not much you can do. But yes, I try to go to their level. I never explain things in medical terms. I explain things with comparisons. For example, when I'm explaining an immune disease, which is a difficult concept to understand, I tell them that you have an army and the army is your immune system and we have different branches such as the army and navy. I explain how each system works and the job of each cell. An example I use the most when I'm trying to explain to a child that he has ADD, I ask them if they play sports. They usually say "Yes", and then they say something like soccer. Then I ask what would happen if they showed up to a game and their coach didn't show up? No parents...just the kids. Then he would say that they wouldn't know what to do. Then I say, "Who do you think is your body's coach?" and he'll say "My brain". Then I say that when he wakes up he is like a soccer team without a coach. Everybody's there...all the components are there but there's no one telling them what to do. So, I say that sometimes we have to wake up the brain so that in the

morning when we wake up and go to class, the brain is not asleep. Then you can pay attention.

...It was just by talking to people and saying, "Why do you do that." For example, we have a lot of Indians from India and I ask them why they put the cord around the baby's belly and why do they put the dot on their forehead and what does this mean and things like that. I just ask because I want to know why they do that.

Participant Four stated the following:

Those areas are difficult to deal with. You do the best you can to try to explain to them in terms that they're going to understand. If it's an English thing, I even have looked for somebody in the building that speaks Spanish and there is one of our nurses who is good at speaking Spanish.

...The toughest one I ever had was a Japanese family who spoke almost no English. I couldn't get anybody to translate so I struggled and that family, fortunately, didn't have a developmental problem. It was just ear aches and sore throats. I don't know what I would have done if it was a developmental problem. For that family I would have had to go out into the community. Those folks did have a relationship with other Japanese people within the community and one time we were discussing a problem and the parents didn't understand and they gave me the name of a friend to call and talk to and I communicated through that 3rd party. It was just people that they knew in the community that they were close with and that's kind of the way I approach it...But most of the time I can find someone to interpret for me.

Participant Five stated the following:

Well, in terms of the language barrier, that's a difficult one because none of my staff speak Spanish. But, there are receptionists that we can find to help translate, which I know is not the best situation. I also draw a lot of pictures to help them understand also when they apply.

...That's about it. I had a family from Sierra Leon and they spoke French. We used Google Translation to communicate with the patient. You can put it in English and it will translate it to whatever language...It made it a very long visit [laughing].

...Asthma. I'll draw the lungs and the airways and how they constrict. I'll draw reflux.

Participant Six stated the following:

I draw a lot. I'm a visual person so I use drawings to help them understand. For example, if someone has a urinary tract infection, I will draw the kidneys and explain how they function to help the parent understand. We also use Spanish handouts that we give the families who speak Spanish. Some of our residents may be able to help translate.

Parent awareness. Each general pediatrician within this study indicated his or her course of action when attempting to educate and increase a parent's awareness of their child's functioning. General pediatricians often facilitated discussions with parents to assist with this goal. Rating scales were mentioned as indirect teaching tools which question parents about age-specific milestones that, if typically developing, their child should be able to do. Additional methods of increasing parent awareness include the

implementation of a parent-child reading program (i.e., Reach Out and Read), the provision of handouts, books, and websites, and the demonstration of strategies to help a child's development within the home environment.

Participant One stated the following:

Well, most of the time if we, for example, let's say for the kid who needed more stimulation to talk...one is giving them examples. If the kid is behind on speech and needed some more reading time or book time, we participate in the Reach Out and Read program. So, from six months on, we have books through a grant that we basically provide to the kid at the end of the visit to encourage parents to read to their kid.

...Now, as far as if a child has developmental problems and we need to refer and have to present those...most of the time some of those kid's parents may not really suspect it but they have other kids and realize that their child was able to walk earlier or was talking by now. Or, they might bring it up anyway so they might be suspecting something. We may say, "Yes, you're absolutely right. It looks like he or she should be doing more." If it's something mild that they can work with at home, we just give them examples of what they can do or handouts by saying, "Here's some other ways you can stimulate them more." But if they're really delayed and they need to be referred, we basically explain to them what Early Steps is and they get to see a doctor and physical therapist or speech. Sometimes, depending on the parent's reactions, like if they feel that it is one more thing they must do, sometimes I reassure them by telling them to go for the first visit because they may evaluate their child and decide that he's ok. Or, they

might need a few times a week therapy, but you don't need to come to the center. We can teach you what to do at home. So, I reassure them and encourage them to go to the first evaluation so they don't neglect their appointment. I say that it might be just a one time thing or you might need to take your child a couple of times a week for therapy. Or, if your child's in a school, they might do their initial assessment and they might recommend that the therapist in the school does the therapy two times per week. So it's usually through handouts, examples, demonstrations, etc.

...When we find a disability in a child, we talk to them about the different options and therapies. In cases of ADHD, we give them a lot of handouts on behavioral management and information on books for parents to read about ADHD, like a list of books and ADHD websites...So it's really more through verbal education or tangible things like handouts or websites.

Participant Two stated the following:

I think the ASQ has helped a lot of our families because they go through and say, "Oh, my kid should be able to do this or that" and they may not have realized it before when we asked them the developmental questions, just as part of the screening. They say, "Oh, I didn't know my kid should be able to do that or he's already doing that."

...The other, not as direct as screening...we're involved with the Reach Out and Read program here so we give children six months to five years old developmentally appropriate books and we encourage parents to read with the child. As we're doing that we say this will help the child read better. Early

literacy increases their chance of doing well at school. So, we bring up that component of it as well, a little bit less directly.

Participant Three stated the following:

...I'm big in preventing...I give them this big speech on how to, from day one, start structuring the house. The baby's life needs to be structured. The baby needs to learn how to sleep. The baby needs to soothe himself. I talk to parents about the different developmental stages and how children learn behavior. The first five years is imprinting, the second five is mostly imitation, and then comes socialization. I am big on the imprinting part because they need to learn that "no" means "no" and "yes" means "yes". Don't make a promise you cannot keep and don't make a threat you cannot follow through with. Be consistent and don't fight every single battle. When you do decide to fight you need to win. I tell them they need to do that before the age of three because after this age, it becomes more difficult. I am very big on that so, with the early children I try prevention a lot. I tell them not to fight over eating habits and not to give the child too much power.

...Sometimes I give the speech and the parent decides that I'm not the type of pediatrician they like. They go to one of my partners and they come back in about four or five years with a rotten child and they want me to fix it and it's too late. But, I tell them this is what they can do. I follow many children from birth to young adulthood. My goal is to prevent them from getting in trouble and that the parent maintains an open channel of communication...I do a lot of parent training but that's because I like it.

...Most parents here know more than we do because they know their child has

problems and they have gone to the internet and learned everything there is to know about that. Then you have the parents that you have to tell them to go to the school because they are entitled to this and that.

Participant Four stated the following:

Most of the time the moms are suspicious and if I see something I'll ask if they're concerned about something and they'll say, "Yeah, I'm glad you brought that up." I watch to make sure that there's truly a problem before I bring it up because I don't want to put something in mom's mind that shouldn't be there. But, most of the time they know and as you start to bring it up, they jump at the chance to talk about it. Then I'll say how about we go over to USF and get evaluated. They'll do some tests and some blood workup and depending on what they find, they may do more. Or, they may say that they haven't found any concerns.

Participant Five stated the following:

We're part of the Reach Out and Read program so I have a grant to give out books at every well-child visit. I really emphasize even more than normal, reading to them. If they indicate wants by pointing, I tell the parents to verbalize the words several times before they give the child what they want by pointing. In the rooms, there are brochures they can take for ADHD and stuff like that.

Participant Six stated the following:

I explain the best I can what the concerns are and we have several resources such as Early Steps and FDLRS and others that we refer to as concerns arise.

As a part of increasing parent awareness, general pediatricians also were asked about their ability to interpret reports from other consultants (e.g., speech language

therapists, psychologists, etc.). With the exception of Participant Five, general pediatricians typically expressed their competence when interpreting reports for families. Some reported that they simply review the results, while others provided the manner in which they hold these discussions. Phrases such as, “I interpret the findings in a reassuring way”, “I think about how I would want it interpreted”, and “When I was a patient, I held on to everything the doctor said” denote a need for a sensitive approach when providing results to parents. The following responses were noted as methods used by general pediatricians to assist parents with the awareness and comprehension of their child’s concerns.

Participant One stated the following:

We go over it with them, like especially when the testing happens in the school and we get back the report with all the scores like the verbal score, assessment score, and usually there is an impression and usually they want to know what it means. So, we go over it with them.

Participant Two stated the following:

Every so often the family will bring in a report from the psychologist or therapist and they’ll say “Here.” So, we’ll go through it and say they seem to be finding this and what they really want is for your child to get therapy or to see an ENT doctor or whatever it is to help the child.

When asked if she has been able to accurately interpret reports from other professionals for the parents of her young patients, Participant Three indicated, “Yes.”

Participant Four stated the following:

I get that all the time. A little girl got an MRI and they told them it was abnormal.

There were problems and mom called and asked me to interpret it for her. Frequently, when I've referred them to someone like a specialist and they found a problem, they come back to me for reassurance and interpretation. I interpret the findings in a reassuring way so they understand that there's a problem but we can fix it. They come back to me because I've been there all along. They trust me more than the high powered guy who obviously knows a lot more about the disease and treatment, but I get feedback from the specialist and then feed it to the parents. They hear the same thing from me that they heard from the specialist, but because I know the family and I've been with the family, it's different. I try to present it to them positively no matter how difficult the results are and talk them through the steps.

Participant Five stated the following:

I will get whatever assessment that's been done across the street. So I get that and sometimes they will bring in school performance report cards or letters from teachers and the concerns that they have.

After further probing, Participant Five reported that she feels uncomfortable when she must interpret reports typically coming from the child development or school settings.

Participant Five stated the following:

In terms of some of the various developmental testing that gets done, I don't feel extremely confident in being able to interpret it and discuss it intelligently.

Participant Six stated the following:

I put myself in their place. Before I was a doctor, I think about how I would want

it interpreted. I see parents and they are waiting for the doctor. When I was a patient, I held on to everything the doctor said. I help explain lab results to parents but I don't always get reports. But as a primary care physician, I've helped patients read speech language reports and other reports. I just give them the bottom line.

Connecting with community resources. General pediatricians within this study reported several ways by which they maintain relationships with community-based resources while continuing to care for their young patients. First, the mere act of consistently referring to a resource has strengthened this relationship. Second, general pediatricians stated that they receive assistance from staff members (e.g., social worker or pastoral care) to maintain this connection. Third, it was reported that holding a leadership role within the community and having a relationship with public school personnel also have assisted with implementing maintaining this goal. Participant Six, due to her setting (i.e., hospital) and specific job requirements, did not report any activities regarding this guideline.

Participant One stated the following:

As for the screening techniques, I don't think I've had more opportunity to do them. I'm not too far up to date on new things because, like I said, we don't practice using them. If I were in the community where there were no Early Steps, I would have to use it more and I'd be more familiar. Those are the things you end up referring.

Participant Two stated the following:

Being on the Board of Directors for [organization], I know the people there.

Sometimes I've called them as well and found kids that we need help with and see if we can get them in sooner or see what else we can do for them. Those are the primary mechanisms that I use.

Participant Three stated the following:

One of our patients is a school board person and she is fantastic and I call her too. I tell her I have a kid with this problem and ask what I can do. And she tells me to tell them to give her a call or write me or fax me and I'll look at the case.

Participant Four stated the following:

I'll use Child Find a lot and I use the Early Development Program over there... Child Find is a good place to start. They'll do hearing, vision, and developmental assessment...

Participant Five stated the following:

...there's no point person. The social worker was hired to work with adolescent physicians in the HIV program. He's just a great resource of all the community resources so, when I really have a problem, I call him.

Participant Six stated the following:

...we have access to a social worker and pastoral care to talk to families and comfort them.

Barriers to Implementing AAP Guidelines.

According to the online survey entitled "Young Children with Delays and Disabilities" and the protocol used during the interview process, general pediatricians were further asked their beliefs about barriers to the implementation of AAP guidelines within their respective setting. An analysis of the data showed that barriers have hindered

general pediatricians from receiving reimbursement for preventive care, administering and scoring screening tools, referring families to community resources, receiving staff assistance during developmental surveillance, and budgeting for the cost of screening tools. However, these same barriers have been overcome, according to statements made by other general pediatricians within this study. In particular, referring families to community resources was considered a barrier by one out of six general pediatricians. Additionally, scoring valid screening tools was perceived as a barrier by four out of six general pediatricians. The remaining four barriers (i.e., administering valid screening tools, assigning office staff to assist with developmental surveillance, financing the cost of standardized instruments, and obtaining reimbursement for preventive services) were perceived as the greatest barriers for five out of six general pediatricians, respectively (See Table 6).

Table 6. Ratios of 6 General Pediatricians Reporting Existing Barriers

My office staff is currently able to...	Ratio of 6 General Pediatricians: Online Survey Data	Ratio of 6 General Pediatricians: Interview Data
...administer valid screening tools	1 out of 6	3 out of 6
...score valid screening tools	2 out of 6	3 out of 6
...assign office staff to assist with developmental surveillance	1 out of 6	2 out of 6
...finance the cost of standardized instruments	1 out of 6	3 out of 6
...refer families to community resources	5 out of 6	6 out of 6
...obtain reimbursement for preventive services	1 out of 6	1 out of 6

Overcoming Existing Barriers to AAP Guidelines

General pediatricians within this study provided information regarding the

barriers they have overcome within their respective settings as well as those they continue to face on a daily basis. Using each interview participant's online survey results, the researcher questioned general pediatricians by probing them to provide information as to how they have overcome barriers and why barriers continue to either exist or not exist within their settings.

Barriers to administering and scoring valid screening tools. The interview participants were first asked about barriers to administering and scoring valid screening tools. Participants Four, Five, and Six reported on the online survey and during their interviews that these two barriers continue to exist. As previously noted, Participant Four stated that he chooses not to use developmental screeners, Participant Five reported that she is faced with time constraints and limited staff, and Participant Six indicated that she does not use developmental screeners as part of her role within the hospital setting. Additionally, Participants One and Three reported administering and scoring valid screening tools as continuing barriers for them, although they simultaneously provided information as to how they have attempted to overcome these barriers. Participant Two was the only general pediatrician who reported overcoming these two barriers in both the online survey and during the interview.

When asked about ways they have been able to effectively administer and score valid screening tools, Participants One, Two, and Three commented on the feasibility of administration, scoring, and interpretation of screening tools, the effectiveness of using questionnaires that screen for multiple concerns, and their ability to develop creative strategies for increasing assessment time.

Although Participant One did not indicate that his office staff had overcome the barrier of

administering screening tools, he provided the following remarks during the interview:

...maybe we've figured out a way in the process...when to do it in the visit...finding a good time so it's not really an additional time. Putting it somewhere in the visit where there is dead time or downtime to really fill it. I think what also helps is having the residents, other than the fact that they already know how to do it, it is also a time while the patients are waiting for the nurse, etc., so residents can do that stuff. So, there's good time management.

Participant One also reported during the interview that he lacks the skills needed to administer more sophisticated developmental screening tools.

Participant One stated the following:

I don't have the expertise to administer, other than the Vanderbilt and a few other ones, other sophisticated tools because its time consuming because we need to be trained.

Participant Two commented on the feasibility of administering and scoring screening tools:

...we have part of the Denver on all well child visits and we give the ASQ to families at certain visits...The ASQ is pretty easy to do and the Denver we extrapolated, just the small portions, we get out answers pretty quickly...Residents also assist with asking questions at well child visits.

...by handing it to the parents, they usually fill it out before they get to the room while they are waiting for the doctor...at least these things are done and then scoring for ASQ is pretty quick.

Participant Three did not indicate overcoming the barriers of administering and scoring

screening tools on the online survey, although she provided detailed information during the interview about how she effectively implements these tasks within her setting:

I also use the Vanderbilt ADHD questionnaire to screen for ADHD. It does have very simple questions that not only screen for possible ADHD, but it also screens for anxiety and oppositional defiant syndrome...It's a scale and very easy to score.

...the reality is that you have to see X amount of patients an hour or else you don't make a living. So, I had to find some creative ways of being able to give them a little bit more time while still seeing patients. Sometimes I do use the forms for them to fill out. I see a couple more patients for ear ache, sore throat, go back and read it...ok, now I need this...so the flow keeps going and I'm still going back and forth to that room.

Barriers to assigning staff to assist with developmental surveillance. Regarding the barriers faced when assigning office staff to assist with developmental surveillance, the main factor which has assisted the interview participants in achieving this goal is having medical residents to assist. Participants One, Three, Four, Five, and Six each indicated this as a continuing barrier for them on the online survey, while Participant Two reported that her staff has overcome this barrier. Furthermore, Participant One (despite the fact that he stated this as a barrier on the online survey), Participant Two, and Participant Six each reported how they have attempted to achieve this goal.

Participant One stated the following:

I think what also helps is having the residents, other than the fact that they already know how to do it, it is also a time while the patients are waiting for the nurse,

etc., residents can do that stuff.

Participant Two stated the following:

Residents also assist with asking questions at well child visits.

Participant Six stated the following:

Yes, we do a birth history and everything. But one of those is a full developmental history and then we do a physical exam. Our residents also help with this.

Participant One also perceived assigning office staff to assist with developmental surveillance as a continuing concern, although he previously described how his staff has been able to overcome this barrier on the online survey. Participant One attributes continuing concerns with this barrier to multiple staff duties.

Participant One stated the following:

It's a barrier in our setting because, one, we have so many physicians and residents and parents already wait so long between the registration and they're waiting to be checked in and the staff is busy doing too many things and to add one more thing for them to do is probably still a barrier for us. But for others I know, it's do-able if you have a small practice with two nurses and three doctors or something. So you could probably train the nurse to ask those questions.

Participants Three, Four, and Five reported reasons for this barrier continuing to exist within their work environment. The number of staff and time management were indicated as challenges to assigning staff to assist with developmental surveillance.

Participant Three stated the following:

Not enough staff or time for additional things.

Participant Five stated the following:

...in terms of support staff, I have one nurse to do everything. So I can't even ask her to do that.

...we work exclusively with medical students seeing patients and then making sure their work is correct and they're generally much slower, so it wasn't a feasible situation to turn over the rooms quick enough...I only have two rooms.

Additionally, Participant Four noted that he does not have a need for additional staff to assist with developmental surveillance.

After clarifying that this is not a barrier for him because he is able to do these activities himself, Participant Four responded by saying:

Correct. I do my own.

Participant Six reported that assigning office staff to assist with developmental surveillance is not an activity that occurs within her specific setting.

Barriers to budgeting for instrument costs. Regarding the task of budgeting for the cost of standardized instruments, Participants One, Three, Four, and Five reported this as a barrier on the online survey. Participant Two, however, did not indicate this as a barrier on the online survey and provided further information during the interview.

Overall, general pediatricians within this study reported their ability to obtain inexpensive and free tools via the internet, create their own tools based on existing measures, and obtain tools through grant studies.

The following quote from Participant One shows the challenges faced when having to pay for the cost of screening tools. As a result, Participant One reported

creating screening tools from standardized versions to assist with screening.

Participant One stated the following:

We couldn't use the Conners' because we had to order them from the company and pay for them and who is going to pay for them? I mean, I might get reimbursed for the screening visit but they're more expensive. We collect for Medicaid in a 10-15 minute visit anyway. So that's why we ended up going with the Vanderbilt and we created our own sheets based on the Vanderbilt.

Participants One and Two further stated that they have obtained valid screeners via a grant study that was conducted within their area:

Participant One stated the following:

So I guess we overcame it in some way and maybe some other ways like, I think the Ages and Stages questionnaires, I think we order them, but I think initially [doctor] paid for the questionnaires from her grant for a study.

Participant Two stated the following:

[Doctor] has a grant that she's doing and she will bring us ASQs...it's not a very expensive test to do.

Participant Three, however, provided information on how she has obtained free materials for screening concerns via the internet:

This article from last year discussed how to screen specifically for Autism and depression and directed us to a web site (brightfuture.org) which these forms could be downloaded for free and used in the practice. I immediately implemented those forms and started using day to day. I downloaded the M-CHAT (a screening tool for the detection of early autism), BECK (a screening

tool for depression) and this PEDIATRIC INTAKE FORM that I found extremely helpful during my initial intake of a patient with behavioral or academic problems.

Participants Four, Five, and Six do not use developmental screeners within their respective settings. Therefore, budgeting is not an issue for them.

Barriers to referring families to community resources. One general pediatrician, Participant Five, reported on the online survey that referring families to community resources continues to be a barrier. However, all six general pediatricians provided feedback on how they have attempted to overcome this barrier. Responses included having additional staff members to take on this responsibility. Specifically, Participants One, Two, Three, Five, and Six mentioned their access to a social worker, case manager, nurse, and/or pastoral care to assist with gathering information, referring families to community resources, and providing support services.

Participant One stated the following:

I think one way is through our social worker going to the school and advocating for testing a child or providing therapy. The other thing, I think Early Steps is the community resource that we use a lot...we have a connection with the university and Early Steps and [doctor] is really part of our [university] position so it makes it a little easier.

Participant Two stated the following:

We have a case manager who is able to get a lot of the resources taken care of for our families...through our case manager we'll send them for developmental screening...So we write an order for our case manager, who then based on their

insurance, sends them to the appropriate location...She identifies the resources for us that their insurance pays for and if it looks more global, we'll send them to Early Steps.

Participant Three stated the following:

We had a nurse here whose child had severe psychiatric problems and she took special interest in finding out resources that were available and that was her cup of tea...to do all this stuff. So we have that.

Participant Five stated the following:

...there's no point person. The social worker was hired to work with adolescent physicians in the HIV program. He's just a great resource of all the community resources so, when I really have a problem, I call him.

Participant Six stated the following:

...we have access to a social worker and pastoral care to talk to families and comfort them.

Participant Four reported that he is able to consult with his peers regarding community resources for children and families:

We have several pediatricians in our group. We talk with each other and we have meetings. I'll say, "I've run into this problem...have you run into that yet?" and they'll say, "Yeah, I've found this source was good. Other pediatricians in the community and in our group are helpful with that.

Barriers to obtaining reimbursement for preventive care. All general pediatricians, with the exception of Participant Five, reported on the online survey that obtaining reimbursement for preventive care remains difficult. Participants One, Two,

Three, Four, and Five honed in on the challenges with reimbursement that they continue to face. Participant Six noted that reimbursement for preventive care is not a concern within her setting.

Participant One stated the following:

Some places may not reimburse you for administering a psychological test because you're not a psychologist. They only allow you certain codes so you can't bill for something even if you're trained to do it. So, I think if you can do some of the tests yourself, it might be faster and more convenient to the family because you could do it right there. You don't have to wait twelve weeks to get seen by someone. But training, reimbursement and time can be a problem.

...if you don't have better resources in the community and if you know how to do it yourself, it's going to add 20 minutes to your visit and you're not going to get reimbursed for it regardless. So, even if you schedule this child and say come tomorrow because I have this waiting room full of kids to see and I need another 20 minutes to do an assessment, you're not going to get paid for it. The insurance company won't pay for it because its preventive service or they decide they won't pay for it. So, that's another barrier.

Participant One also provided a possible solution that would assist with obtaining reimbursement for preventive care:

...an example I'll give is we just started doing varnishes because the AAP wanted us to do oral health as a primary care physician. In North Carolina and some other states, maybe there are 30 states in the country, Medicaid actually reimburses physicians for a CPT code that's a "D" code for Dentist to apply

varnish. Before Medicaid wouldn't do it and there's been some lobbying from the dental society to allow pediatricians to submit those codes and get reimbursed and Medicaid won't do it just because you're not the specialist. Even though the fluoride varnish application is like painting teeth, in some communities and schools, school nurses could do it. You don't even need a physician to do it. So, I could see even on the flip side even if somebody in an office who knows how to administer some of those sophisticated tests and is willing to pay for that, if they can't get reimbursed, they might not do it...

Participant Two stated the following:

Insurance companies will sometimes limit the number of tests or they'll limit the number of providers that we can refer our kids to and if they're too far away for our families and they can't get there, they may only pay for ten speech therapy visits and the kid needs a lot more than that and we can't get paid for it. So, then we're trying to either send them to some other community resource to try to hopefully get it paid for or get it for free or get it done through the school where it doesn't cost anything, but getting the testing can be quite a barrier

Participant Three stated the following:

...Because they don't pay for the amount of time. Some kids need an hour but they're not going to pay for it. I cannot charge for an hour worth of mental health. Mental health is something that the insurance company won't pay for period.

Participant Four stated the following:

More families can't afford insurance. They can't get Medicaid because they make too much money. So, those families are having a hard time just getting in for

routine checkups and sometimes immunizations. Just basic things can be a problem.

...The vaccine for children problem is a real help if a family has no insurance. I can use Vaccine for Children to get vaccines. They don't like to go to the health department because there's a stigma associated with going to the health department. But just to come in for a checkup is expensive, especially if you don't have insurance.

While Participant Five reported that obtaining reimbursement for preventive care is not a barrier within her setting due to interval-scheduled well-child checks, she did mention concern for immunization reimbursements:

The first one technically is at the two week visit, but we usually see kids before then out of the hospital. Then two months, four months, six months, nine months, one year, fifteen months, eighteen months, and then two years and every year thereafter.

...There have just been some issues with immunization reimbursement that it doesn't even cover our cost some times. If the immunization cost is one hundred dollars and the insurance gives us one hundred dollars back, that doesn't cover any overhead such as the cost to administer, space for refrigeration, etc.

Additional barrier: low socio-economic status (SES). At the culmination of each interview, the researcher asked general pediatricians to inform her of any barriers that had not been discussed. Participant Two stated that families from low SES backgrounds often face difficulties that create barriers to receiving effective care for their children.

Participant Two mentioned changes in addresses and telephone numbers and a lack of

transportation as examples. The remaining participants did not provide information regarding additional barriers.

Participant One stated the following:

Referring really is a pain because a lot of our families are from low socio-economic status and sometimes they'll make up addresses, phone numbers, or their cell phone will be good for an hour after their visit - then its gone. So, you're trying to contact them again and send them to the speech therapist or here's your appointment for this and they never get the letter. They don't understand it, they ignore it, or transportation is broken down so they can't get to the appointment They have two other kids that had issues at the same time so that kid fell to the wayside. So, that's the most frustrating part. Not only referring, but getting them to the actual place on a consistent basis. It's often very difficult for our families. ...I have one kid, its been six months now that we had referred him to the speech therapist and audiologist four different times and the mother said she's never gotten letters, never gotten phone calls, we refer again and the same thing again. This kid is behind. He's been behind six months! I don't know what else I can do except try to get the case manager and her hooked up at the same time. Hopefully they have the same number for 45 minutes. Unfortunately, this issue is very real and that's probably the most frustrating thing."

Additional barrier: general pediatricians' beliefs. The researcher noted that negative perceptions held by general pediatricians within this study regarding developmental screeners and/or while dealing with children's behavioral issues can serve as possible barriers towards the implementation of AAP guidelines. The barrier of

perception arose due to Participants One and Four providing statements regarding the use of developmental screening tools within their settings.

Participant One stated the following:

It's almost like me doing someone else's job...if it's not required then you don't do it.

Participant Four stated the following:

I don't use a lot of screening techniques. I have not been one that uses those. I have not found them very helpful...They're time consuming and I don't have a lot of time to do them, and when I'm through, I'm not sure what I've accomplished other than what I see when I examined the patient and talked to the mom. I used to use it when I first started. I really didn't find them that useful. I just went on clinical evaluation because they really didn't add much.

The researcher further questioned Participant Four concerning his interactions with individuals within the school system.

Participant Four provided information about his concerns while working with parents and school staff in the process of identifying children with AD/HD:

My contact with the school system is mostly with kids having ADHD, which I have decided that I don't do. It's a very complex problem and I have just gotten out of doing ADD. But when I was doing that, they were contacting me through the parents indirectly, trying to get the kid on medication. It could be the teacher or the school psychologist who thought the kid needed to be on medication.

Frankly, I feel that a lot of kids are labeled ADHD and put on medication when they shouldn't be on medication.

Most of the kids are behavior problems in school so they want to calm them down so that they are not disrupting in school. That seems to be their goal. That's how it comes across. As long as a kid doesn't cause trouble in the classroom...that's our main goal. And the parents just want the problem to go away. Give the child a pill and make the problem go away and they don't want to do all the other things that are required. You know, you've got to make sure that the child gets their homework done every night. You've got to make sure that the child is taking his medication...parents...many of them just want the easy solution.

The researcher probed Participant Four in an attempt to gather further insight about his beliefs as to why parents may want "the easy solution". An example proposed by the researcher during this probe was the lack of education.

However, Participant Four clarified his professional beliefs with the following remarks:

It's more like a lack of involvement. Really, they're not involved with their children as before. They go to daycare and they go to work, and both parents work, and mom's not home. I think that's a big problem. I'm sure ADHD didn't just develop...it's been there all along. But mom was home, you had family support and there was discipline. A lot of these attention deficit disorder children can be disruptive. But, if there was pretty strong discipline and structure...that's the way we've made it in the past I'm sure. Many probably didn't graduate from high school, they quit when they were 16, but they all seemed to make it. They all were citizens that were valuable to the community. But the family structure is no longer there. There's no discipline to go to school and if they are disruptive,

there's not much the teacher can do but call the pediatrician to try to put him on a pill to control him. I was very displeased with that. I decided that I wasn't going to be a "refill Adderall" doctor. Luckily, when I did, we have a child psychiatrist that I refer my school behavior problems to. I don't abandon them, but I have found a place to go.

Summary of Findings

The findings within this chapter demonstrate item- and pattern-level analyses of the responses provided during the survey and interview process. Demographic data obtained within this study reported trends by the specific age range, gender, setting, location, and weekly hours of each interviewee. According to this data, the majority of interviewees were: middle aged, female, have practiced for 10-15 years, are employed predominantly within clinic settings, and work 40-50 hours per week. Furthermore, the interviewees reported working within both urban and suburban locations equally, although no general pediatricians reported working within a rural location. Additionally, the one general pediatrician who worked in a hospital setting (i.e., Participant Six) reported her inability to engage in AAP guidelines and overcome barriers less when compared to her peers. Although Participant Six provided information on several topics during the interview, she was the only general pediatrician who reported that specific activities did not occur within her role in the hospital setting.

An item-analysis of the interviewees' responses to each AAP guideline showed that each of the six general pediatricians reported strategies they implement to maintain their knowledge regarding child development issues, determine the cause of delays, refer children in a timely manner to intervention resources, present information to families

using a culturally-sensitive and family-centered approach, and increase parent awareness and comprehension of their child's current functioning and concerns. Half (i.e., three out of six) of the interviewees reported engaging in activities to increase their knowledge about administering and interpreting developmental screeners while their peers reported either not using developmental screeners within their setting (e.g., hospital), not having the interest, and/or not having the time to use developmental screeners within their respective settings. Most general pediatricians (i.e., five out of six interviewees) reported their ability to interpret consultant's findings for parents when needed. Additionally, five out of six general pediatricians reported that they have maintained a connection with community resources via the referral process, assistance from staff members, and their relationship with other professionals within the community. However, no interviewees provided information regarding their ability to maintain relationships with community resources while, simultaneously coordinating care with them through the medical home.

Several themes identify the areas in which general pediatricians have developed effective strategies for implementing AAP guidelines and overcoming common barriers. These themes are training and continuing education, learning about and using developmental screeners, determining the cause of delays and disabilities, referring children with delays and disabilities, using a culturally-sensitive/family-centered approach, and parent awareness. See Table 7 for additional information regarding themes, descriptions, codes, and examples.

Table 7. Themes, Descriptions, Codes, and Examples

Themes	Descriptions	Codes	Examples
Training and Continuing Education	Methods by which general pediatricians stay updated about child development issues, risk factors, etc.	Meetings	Receive brochures from community resources
		Print Media	PREP – Pediatrics Review and Education Program
		Internet/Email	Residency
		Consultation with colleagues	Reading lay press and medical magazines
		Training	Attend national meetings/conferences, workshops, lectures/grand rounds
			Phone calls
			Journals
			Online articles
			Websites
			Email Correspondence/AAP listserv
	Audio Digest		
	Brochures		
Learning About and Using Developmental Screeners	Methods by which general pediatricians have gained skills to administer and use developmental screeners	Residency Training	Reading articles
		Independent Learning	Buying/downloading tools from websites
		Grant Study	Attending Lectures

Using a Culturally-Sensitive/Family-Centered Approach	Methods by which general pediatricians have communicated information with parents using a culturally-sensitive/family-centered approach	Modeling Print Media Translators Discussions Drawings	<p>Draw picture of UTI infection, asthma</p> <p>Demonstrate to parents how to interact with their child</p> <p>Discuss with child (and parent) ADHD</p> <p>Utilize the friend of a family (e.g., Japanese) to help with communication</p> <p>Utilizing Spanish-speaking residents/staff members</p> <p>Provide handouts in native language</p> <p>Google Translation</p> <p>Pastoral Care</p> <p>Explaining concepts in basic terms</p> <p>Learning about culture/background</p> <p>Parent training</p>
Determining the Cause of Delays and Disabilities	Methods by which general pediatricians determine the cause of delays/disabilities	Screening and Surveillance Consultation	<p>Make observations, conduct interviews, and administer screening tools</p> <p>Consult with professionals (e.g., developmental pediatricians, neurologists, teachers, social workers and school psychologists)</p>
Referring Children with Delays and Disabilities	Methods by which general pediatricians engage in the referral process with community resources	Transitioning Children	<p>Social worker follows up with the school for testing, classroom interventions, etc.</p> <p>Provide parents with phone numbers</p> <p>Fax/send referral</p> <p>Write prescription for testing</p>

			Assist parent with finding additional resources if current resources (e.g., psychologist) is unavailable
			Make a follow-up call to speed process of getting seen by developmental pediatrician, etc.
			Send to developmental pediatrician if the school is unable to test immediately (for school-age children)
Connecting with Community Resources	Methods by which general pediatricians stay connected with community resources while managing (through the medical home)	Staff assistance Leadership role in community	Social worker visits school to advocate for testing Staff member stays updated on resources Serve in a leadership role for child-centered organizations
Parent Awareness	Methods by which general pediatricians increase parent knowledge	Interventions/Therapies Print and Internet resources Questionnaires Programs Discussions	Discuss interventions and therapies that can be done within the home Provide handouts, books, websites on behavioral management, ADHD, etc. Completing the ASQ has helped parent awareness Interpreting Reports Reach out and Read program Discuss parental rights within school system, etc. Discussions with parents about child development

An analysis of barriers showed that all six general pediatricians reported that their staff is able to refer families to community resources, whether they are able to provide the information themselves or a staff member assists. Three out of six interviewees indicated that their staff is able to administer and score valid screening tools, as well as afford the cost of these tools. Finally, two general pediatricians reported their ability to assign office staff to assist with developmental surveillance and one general pediatrician indicated her ability to obtain reimbursement for preventive services.

Table 8. Overcoming Existing Barriers

Objective	Barriers	Solutions Provided by General Pediatricians
Administer <u>and</u> Score Valid Screening Tools	Insufficient office time to administer standardized instruments	Residents assist with administering and scoring screening tools
	Lack of nonphysician staff to assist	Use tools that are easy to administer and score (e.g., ASQ, Vanderbilt, etc.)
	Perception that screening tools are not necessary or “someone else’s job”	Have parents fill out screeners while waiting for the doctor, nurse, etc. Make the use of screening tools mandatory
Obtain Staff Assistance with Developmental Surveillance	Lack of nonphysician staff to assist with developmental surveillance due to job demands and/or time constraints	Residents assist with developmental surveillance
Budget for the Cost of Standardized Instruments	High cost of instruments	Download screening tools for free via the internet
		Use inexpensive screening tools
		Obtain screening tools for free via <u>participation in grant studies</u>
Refer Families to Community Resources	Lack of knowledge of community resources	Staff members assist with supporting families and connecting them to resources

Additional information about barriers was obtained by the general pediatricians within this study. While all interviewees reported difficulties with reimbursement for preventive care, one general pediatrician (i.e., Participant One) provided a possible solution to this concern using dentistry as a model for change. One general pediatrician (i.e., Participant Two) indicated the difficulties experienced while serving low SES children and families. Furthermore, one general pediatrician (i.e., Participant Four) stated his continued frustration with guiding parents and teachers through the assessment and intervention process for children suspected of having AD/HD. See Table 9.

Table 9. Continuing Barriers

Objective	Barriers	Possible Solutions Provided by General Pediatricians
Obtaining reimbursement for preventive care	Lack of reimbursement from insurance companies for preventive service Using billing codes for reimbursement of preventive care	Allow general pediatricians to submit reimbursement codes for preventive care procedures similar to the “D” code used for fluoride varnishes typically applied by Dentists
Serving Families from Low Socio-Economic Status (SES) backgrounds	Transportation difficulties Address and phone number changes Families have difficulty affording insurance	Not provided
Working with Parents and Educators for the Assessment and Intervention of AD/HD	Belief that parents and educators want children diagnosed with ADHD/ADD as “the easy solution”	Not provided

A final analysis of the interview responses showed that general pediatricians could be categorized into one of two groups. Specifically, Participants One, Two, and Three provided detailed responses indicative of their extensive knowledge of the AAP guidelines and experience with the consistent implementation of these guidelines.

Participants Four, Five, and Six expressed greater difficulty with implementing AAP guidelines as compared to their colleagues. These concerns may be attributed to a variety of factors, such as time, available personnel, and training in using developmental screeners. Regarding Participant Six, her pattern of responding is primarily attributed to her particular work setting (i.e., hospital). Based upon these findings, this researcher believes that each participant's responses were authentic and representative of their personal experiences, perspectives, and practice environments.

Chapter Five

Discussion

The researcher's position regarding this study is that the interview participants have found methods of assisting children in need, despite the obstacles faced. However, these obstacles could be less prevalent if increased collaboration among disciplines occurred, in addition to systemic changes. Also, these changes could lead to increased consistency and effectiveness in providing early identification and intervention services for young children with delays and/or disabilities. The purpose of this study was to gain a more comprehensive understanding of the struggles and triumphs general pediatricians have encountered in their efforts to follow best practices while serving young children having delays and/or disabilities. An additional objective of this study was to determine the barriers overcome and those that continue to pose difficulties. A final goal of this research was to engage general pediatricians in a discussion about their relationships with professionals both within and outside the health field.

Research Questions

Five research questions were posited in an effort to determine the extent to which AAP guidelines are successfully implemented by a sample of general pediatricians. It was found that all general pediatricians within this study, regardless of setting, were able to report their engagement in some, if not all AAP guidelines. Specific strategies, procedures, and thought processes for overcoming barriers were relayed to the researcher by each general pediatrician for a variety of topics and concerns. The following section

addresses each of the research questions for this study, followed by a discussion of the findings.

Research Question One:

What strategies and procedures are general pediatricians implementing (e.g., using developmental screeners to identify children's needs, referring children in a timely manner to intervention services within the community, etc.) to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?

Implementing AAP guidelines. The implementation of all nine AAP guidelines (i.e., strategies and procedures) was demonstrated throughout this study. Therefore, this sample of general pediatricians was able to engage in successfully screening, diagnosing, referring, and case managing young children with developmental concerns. These strategies ranged from engaging in independent activities (e.g., keeping abreast of current issues and literature within the field of pediatrics, seeking knowledge about administering screening tools, etc.) to activities requiring the assistance of other professionals (e.g., referring children to resources with the assistance of a social worker, consulting with professionals regarding a child's concerns, etc.). However, concerns were noted by the participants regarding the usefulness, time factors, and finances available to conduct of developmental screening tools, developmental surveillance, reimbursement, working with low SES families, the interpretation of consultants' reports, and working with families and educators to diagnose and intervene with children having (or suspected of having) a diagnosis of Attention-Deficit/Hyperactivity Disorder (AD/HD).

Research Questions Two, Three, and Four:

What specific barriers have general pediatricians encountered, how have they overcome

these barriers, and which barriers continue to prevent general pediatricians from the ability to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?

Developmental screening and surveillance. Although general pediatricians within this study reported that residency training, independent learning, and participating in grant studies are methods by which they have learned about and implemented the use of developmental screeners within their settings, there are some concerns that exist. For example, once residency training is complete, opportunities for systematic and structured learning opportunities quickly decrease. Additionally, opportunities to obtain and use developmental screeners via participation in grant studies and/or through independent research efforts to increase one's learning are not widespread and appear to be happenstance events. Consequently, access to more systematic and structured training sessions on developmental screening tools and techniques may be required to increase the uniformity of learning for general pediatricians.

Despite the research supporting the use of validated screening tools, some interview participants remained unable to use these tools within their settings due to barriers (e.g., time constraints), or they choose not to use them. Additionally, some general pediatricians reported creating office-based checklists or abbreviated versions of tools that may have compromised sensitivity, specificity, validity, and reliability when detecting developmental concerns. A modified version of the Denver, for example, is a tool that was mentioned throughout this study. First, Tervo (2003) stated that cautious use is recommended for the Denver II because it may not detect concerns specific to cerebral palsy in a child's first 12 months of life. Furthermore, Tervo explained that office

checklists aren't recommended, because they do not frequently identify developmental or behavioral concerns. Therefore, it is important that general pediatricians have an understanding of a tool's ability to effectively detect concerns before implementing its use and refrain from modifying the format of the tool. These factors (e.g., reliability, sensitivity, etc.) also would apply to screening tools that are obtained for free via the internet. The Modified Checklist for Autism in Toddlers (M-CHAT) and Beck Depression Inventory were mentioned as tools obtained through the internet. However, there are likely several other tools that may be downloaded from the internet whose reliability, validity, specificity, and sensitivity are unknown. Prior to using these tools in practice, general pediatricians should be aware of which tools are appropriate for use.

Modifying a tool not only compromises its psychometric properties (e.g., sensitivity, validity, etc.), but also makes it difficult to engage in accurate and repeated measures of a child's development. Using appropriate screening tools in their entirety can assist all current and subsequent professionals (e.g., medical, educational, etc.) in accurately assessing a child's developmental growth. Additionally, the use of appropriate tools across professionals would decrease the chances of parents and/or caregivers receiving unexpected information regarding their child's developmental patterns. This discussion, however, can lead to another important question: How can screening tools be used when some general pediatricians are unable to afford them within their settings? General pediatricians within this study reported that using low-cost screening tools (e.g., ASQ), obtaining free tools via the internet, and/or participating in grant studies are methods by which they have obtained screening tools.

General pediatricians within this study also reported difficulties with assigning office staff to conduct developmental surveillance. However, some participants reported completing this activity within their settings through the use of medical residents. Although medical residents are not typically available to general pediatricians in non-academic settings, it is essential that medical residents are provided with opportunities for participating in developmental surveillance that includes administering and scoring screening tools. This experience will ultimately increase their confidence in using these tools throughout their careers. Additionally, it is equally important that general pediatricians who do not have access to medical residents are provided with alternative methods of obtaining assistance with developmental surveillance. For those general pediatricians within this study who had access to medical residents, the task of using screening tools during developmental surveillance was manageable. However, general pediatricians often reported that assigning other office staff to assist with this goal tends to be more difficult. It is possible that some of the general pediatricians who elected not to use developmental screeners may have felt that the task is unmanageable due to their inability to obtain assistance from others (e.g., medical residents, office staff, etc.). This concern could be further remediated via, for example, professionals-in-training (e.g., pediatric school psychologist interns) who are familiar with administering and interpreting developmental screening tools and may be required to obtain experience in multiple settings through their graduate programs. Other individuals (e.g., volunteers) also may be trained to use these screening tools, which would assist general pediatricians with conducting developmental surveillance.

Connecting with community resources. General pediatricians within this study

often reported their ability to refer children and families to community resources via the assistance of a staff member, through major community resources such as Child Find, or through their own efforts. However, the participants' ability to follow-up with these community resources to maintain their awareness of intervention effects and child development tends to be a much more difficult task. To require general pediatricians to initiate communication with and keep track of each community resource that their patients are involved with appears to be a complicated task. For example, time constraints and reimbursement concerns would not enable general pediatricians to successfully engage in this task. However, professionals working within these community resources could help to keep general pediatricians informed by developing a system of communication in which they periodically send the child's parent and/or general pediatrician (with parent permission) reports or brief summaries of the child's most recent assessments, therapies, concerns and/or improvements.

Reimbursement. Insufficient reimbursement for preventive care is a prevalent concern across general pediatricians within this study. The American Academy of Pediatrics (2005) published a Developmental Screening/Testing Coding Fact Sheet for primary care pediatricians, which lists the specific codes for developmental screening, surveillance, and assessment. It also provides a list of the assessment tools, appropriate documentation for testing tools, and sample tools for use. Increased awareness of this and similar fact sheets would assist general pediatricians in obtaining reimbursement. However, in the event that insurance companies are continuing to withhold reimbursement for preventive services (e.g., developmental screening), increased lobbying is needed through the appointment of well-informed individuals who can

effectively represent the current issues, solutions, and projected outcomes on the behalf of general pediatricians and other professionals invested in these concerns. The fluoride varnish example provided by a general pediatrician within this study provides a model for how obtaining reimbursement can be done effectively.

Research completed by Lewis, Lynch, and Richardson (2005) reported medical professionals' initial reactions to administering fluoride varnishes to low-income patients. One interviewee stated, "Why aren't the dentists doing it? Why are you asking physicians to do yet one more thing?" These questions may reflect the thoughts of general pediatricians regarding the use of developmental screeners. As the current study has shown, general pediatricians are already using developmental screeners and have found ways to manage their time effectively. However, for those who are not using these screeners due to, for example, unfamiliarity or insufficient time to administer them, observing a colleague "in action" may lessen these concerns.

Lewis, Lynch, and Richardson (2005) further noted interviewees' comments after observing a fluoride application. One participant stated, "We saw that it wasn't hard to do, didn't take very long to do, gave us mechanics, showed us what to use, and showed us the billing codes, so how we can bill for it..." These statements demonstrate the benefits of modeling when presenting a new concept to individuals who often have time constraints on a daily basis and are unaware of how doing "one more thing" is possible.

Low SES families. Families from low SES backgrounds are often faced with obstacles which make navigating through daily life a difficult task. Likewise, general pediatricians indirectly encounter these obstacles when attempting to effectively care for families living in poverty. Transportation difficulties, address and phone changes, and a

family's ability to afford insurance (regardless of SES status) were provided as barriers within this study. Offering solutions that address these issues may be the most difficult, considering a family's financial status is beyond a general pediatrician's immediate control. However, there may be some alternatives worth pondering.

General pediatricians may elect to implement innovative interventions such as mobile care vans and community screenings to access low SES families who have difficulty obtaining consistent medical care for their children. For example, Campos (2008) reported that the Ronald McDonald Care Mobile Program uses pediatric faculty, medical students, pediatric residents, nurse practitioner students and nursing students to visit schools and shelters on a regular basis. These individuals provide medical and dental services to underserved children within a community located in West Central Florida. Also, general pediatricians within this study often made reference to Child Find as a referral source during this study. Similar to the screenings conducted by Child Find, general pediatricians could partner with local agencies, colleagues, and/or other professionals to provide services such as developmental, vision, and hearing screenings to families in need.

Another option, although less popular at this time, would be for general pediatricians to make housecalls to underserved families. A study conducted by Ingram et al. (1999) showed that physicians typically made housecalls for elderly patients, cancer patients, trauma patients, and patients having transportation difficulties. The researchers further stated that issues such as the lack of insurance reimbursement and time spent making housecalls were concerns for these practitioners. However, Thompson (2002) reported that his practice is growing due to the technological advantages found in today's

society.

Difficulty reaching families from low SES backgrounds was noted as a concern by a general pediatrician within this study. Specifically, families with children having developmental concerns demonstrated difficulty with obtaining consistent care due to financial concerns, transportation concerns, and/or other stressors. Although several factors need to be fully examined and addressed to assist physicians with making housecalls, this concept may serve as an alternative for reaching families experiencing difficulties associated with their SES background, such as transportation. Furthermore, housecalls could benefit the children of parents who have difficulties due to their elderly status (e.g., grandparent), a physical disability, and/or illness. Making housecalls may be an area of interest for those general pediatricians who are interested in using an alternative method to assist in providing continuous care to some of our most vulnerable children. Additionally, improving the affordability of medical insurance for all children continues to be a nationwide focus that, once achieved, would assist families with receiving proper and consistent medical care for their children.

Interpreting reports. Although most general pediatricians within this study did not indicate the process of interpreting consultant's findings as a concern, it was stated by one general pediatrician as an area of insecurity. It is possible that other general pediatricians are experiencing similar feelings, especially when asked to interpret reports from professionals such as developmental pediatricians or psychologists. This may be due to the fact that assessments used often contain various methods of reporting outcomes (e.g., percentiles, age/grade equivalents, stanines, and standard scores) (Canter, 1998) and technical jargon unfamiliar to general pediatricians. To assist general

pediatricians with obtaining further knowledge on the interpretation of scores and overall reports, it may be beneficial to create brief trainings and/or articles dedicated to explaining how to accurately interpret reports from other disciplines. This, too, would help to ensure that general pediatricians fully understand the status of their patient's medical, developmental, behavioral, and/or mental health while facilitating the medical home.

Research Question Five:

In what ways are general pediatricians collaborating with other professionals (e.g., developmental pediatricians, teachers, school psychologists, etc.) in an effort to effectively screen, diagnose, refer, and/or case manage children with developmental delays and disabilities?

Working with educators and families. One general pediatrician provided information on how he has collaborated with teachers and parents in an effort to assist children suspected of having AD/HD. This individual also expressed frustration while addressing these concerns. Specifically, the belief that parents and educators want an “easy solution” to behavior problems, such as administering “a pill,” was mentioned. As seen in the example provided within this study, this belief has caused one general pediatrician to refer these concerns to a psychiatrist instead of addressing them. This belief and frustration, if held by other general pediatricians, also may influence their decision to refer potential AD/HD cases.

These concerns are valid and may require additional education for parents and educators alike. Foremost, the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (American Psychiatric Association, 2000) describes AD/HD as a

childhood disorder which causes developmentally inappropriate levels of inattention and/or hyperactive-impulsive behavior. These behaviors appear before the age of seven and continue for more than six months. To meet the criteria for diagnosis, there also must be evidence of clinically significant impairment in a child's social or pre-academic/academic functioning in more than one setting. Diagnosis prior to the age of six should be carefully debated, considering children's tendency to be active during the early childhood years. Differential diagnoses also should be made to rule out other possible concerns. Finally, parents and educators need an understanding of the benefits of intervention planning and implementation. In particular, medication usage is enhanced when other interventions (e.g., social skills training, environmental re-structuring, etc.), classroom behavior management strategies, and discipline are provided within the school and home environments.

Collaboration with other professionals. General pediatricians reported their ability to collaborate with other professionals throughout this study. Examples of collaboration provided by the general pediatricians involved calling a colleague for guidance and/or working with a site-based social worker to obtain additional information about a child. In this case, general pediatricians reported their ability to share knowledge with other professionals and work together towards a common goal. Other examples of collaboration that were mentioned by general pediatricians were obtaining information from teachers, school nurses, and few school-affiliated social workers, guidance counselors and school psychologists regarding a child's status. In these instances, general pediatricians often equated collaboration with giving and/or receiving information. Oftentimes, the professional would contact the general pediatrician in an effort to initiate

communication, considering general pediatricians are often unable to dedicate large amounts of time to contacting (via phone) other professionals. Furthermore, general pediatricians would not get reimbursed for these efforts even if time permitted. Although collaboration was often explained as effective, it also was described as rare, especially when working with certain professionals within the school setting.

Finally, general pediatricians within this study often reported their ability to interact with other professionals and community resources for the concerns of young children. However, contradictory results were noted when comparing survey and interview responses for the AAP guideline addressing their ability to maintain relationships with community-based resources and coordinate care with them through the medical home. Specifically, four out of six participants indicated on the survey that they were able to implement this guideline. However, after conducting interviews with each of the six general pediatricians, it was found that none of the participants provided supportive information for this guideline. General pediatricians reported maintaining relationships with community resources, yet none of the participants reported doing this while simultaneously coordinating care for their patients through the medical home. Instead, general pediatricians typically described collaboration as providing and/or receiving information from community resources and other specialists.

Sandler et al. (2001) noted that general pediatricians are to provide leadership for the medical home and as a member of the early intervention team. This leadership role requires consistent communication, problem-solving, and goal setting among the child's family, therapists, and service providers. An examination of all data provided during each interview shows that general pediatricians are implementing the five components of a

medical home reported by Strickland et al. (2004) to the best of their ability. However, experiencing no difficulty in obtaining needed referrals is one of the five components (proposed by Strickland et al.) of the medical home that remains a barrier. Additionally, general pediatricians provided numerous testimonies of how they have insufficient time and office personnel to assist with tasks. This, too, would continue to make the implementation of the medical home difficult. Furthermore, reimbursement for care coordination is not available to assist with implementing the medical home. Given this description, it appears that collaboration of this magnitude may have been more difficult for the general pediatricians participating in this study to achieve. Additional dialogue and/or training in how to coordinate care with community-base resources through the medical home may be beneficial.

However, the American Academy of Pediatrics (2006) provided information on parent's expectations of their child's medical home. Specifically, parents expect the medical home to address their child's continuous and comprehensive care, to be interested in their child's development throughout childhood and adolescence, to identify their child's developmental strengths and weaknesses, and to be knowledgeable of available community resources to facilitate referrals. It was found that the general pediatricians within this study (with the exception of the hospital-based participant due to role differences) are meeting parents' expectations for providing their child's medical home.

Limitations

Limitations were apparent within this study and should be addressed for future research. One limitation of this study is reduced external validity. Because the

participants were drawn from the AAP, results from this analysis may only be viewed in light of general pediatricians who are also members of this organization. Additionally, a small number of general pediatricians were interviewed for this qualitative study. While this sample size enabled the researcher to examine each case as it pertains to the hypotheses and research questions, it did not enable broad generalizations to be made for all general pediatricians (regardless of AAP membership). Tellis (1997) noted this by stating that in analytic generalization, the focus is to compare the case study's results to the previously developed theory, not a population.

Considering the general pediatricians were recruited for participation within this study due to their ability to follow best practices, it is possible that they responded in an overly positive manner during the interview. Yin (1994) stated that responding to questions in a manner that is socially desirable creates response bias. Although, the researcher attempted to address social desirability in responding by assuring the interviewees that their responses would remain anonymous. Despite the limitation of social desirability in responding, the researcher obtained “rich” data – both positive and negative in nature. There are a few possibilities for why this occurred. First, general pediatricians may have viewed the interview as an opportunity to express their thoughts and frustrations in a confidential setting. Also, completing the online survey and reviewing the study's purpose within subsequent emails may have enabled general pediatricians to obtain a greater understanding of the study and prepare for the interview. Additionally, the researcher communicated to general pediatricians via emails and informed consent that they had been selected to participate in an interview due to their “reputation for following best practices for serving young children”. This, too, may have

increased the comfort level of these general pediatricians when responding to interview questions.

Another limitation is that the participants may not have remembered certain information as they were questioned. Additionally, a semi-structured interview was employed within this study, which may have caused the researcher to lose an understanding of how each interviewee would have structured the topic themselves (Bogdan & Biklen, 1992). A final limitation regarded the use of a phone interview to record the responses of one participant. Although this was a method preferred by the participant due to difficulties scheduling a face-to-face meeting, interviewing in person could have allowed the researcher to observe additional cues (e.g., body language) to facilitate a deeper discussion regarding her experiences. Also, technical difficulties occurred during this interview (i.e., phone reception) which caused the researcher to rely on written notes more than the audio recording.

Moving Forward – Assisting General Pediatricians

Despite these limitations, the researcher sought to explore the specific topics and domains presented within the developed interview protocol, in an effort to support the research questions and goals. Utilizing an interview format enabled the researcher to maintain a targeted focus on each case, and provided insight into cases that helped to produce some causal inferences (Tellis, 1997). Specifically, this study provided insight on how the participants have been able to adhere to AAP's recommended practices and what particular issues have interfered with this adherence. Much of the literature has focused on barriers which prevent general pediatricians from engaging in best practices when assisting children with developmental concerns. However, the results obtained from

this study could potentially serve as a guide for other general pediatricians with similar demographics and/or practice concerns. Additionally, barriers that continue to exist for these general pediatricians were noted in an effort to decipher between concerns that can be remediated within the general pediatrician's practice and concerns which may require additional supports (e.g., changes in policy, collaborating with other professionals, etc.).

General pediatricians are implementing several strategies to assist children and families, despite several limiting factors. Their efforts are to be commended, considering the time limit and number of children that must be seen on a daily basis to ensure their livelihoods and the "smooth" functioning of their particular work setting. However, a fundamental point must be made – general pediatricians cannot successfully serve young children and their families without the assistance of policy makers, in addition to parents, educators, other healthcare providers, and specialists throughout the community and within school environments. Each individual (i.e., the parent, educator, other healthcare providers, and specialists throughout the community) can play an important role in helping to create cohesiveness in the care provided to young children. Research on the medical home paradigm highlights the importance of coordinating services among providers to prevent the fragmentation of care – whether medical or psychosocial. Specifically, professionals within early childhood daycares/facilities and elementary schools (serving prekindergarten and kindergarten populations) also can participate in promoting this cohesiveness by facilitating site-based health programs or full service schools which provide prevention and early intervention for children's health concerns, as well as for problems that arise as a result of experiencing health concerns (e.g., pre-academic, academic, emotional, and behavioral concerns). The school-based professional

serves as part of a multidisciplinary team whose focus includes providing child advocacy, direct service (e.g., intervention development and implementation), health promotion consultation, coordination of services, and the development of programs. The school-based professional also can work with other professionals both within and outside (e.g., general pediatricians) the building to accomplish these various goals (Power, DuPaul, Shapiro, & Parrish, 1998). One professional, the school psychologist, can play a vital part in assisting this team with effectively serving children, especially those children who are victims of poverty and underinsurance.

The School Psychologist as a Facilitator of Collaboration

School psychologists are skilled in the areas of prevention, assessment, intervention, and consultation. Additionally, school psychologists work within a variety of settings such as schools and medical facilities such as hospitals and pediatric clinics (Power & Bradley-Klug, 2006). School psychologists also serve as liaisons between teachers, administration, parents, community resources, medical professionals, and specialists within the school and other settings.

Similar to the general pediatrician's role as facilitator within the medical home concept, the role of the school psychologist working with pediatric issues is to assist with the home-school-community connection. Particularly, school psychologists can facilitate the coordination and connection of families with school-based services, medical health services, and mental health services to positively impact a child's development and learning (Sheridan & Ellis, 2006). Power and Bradley-Klug (2006) recommend using an approach to address children's health-related needs that includes servicing all children. This approach consists of implementing prevention efforts for children based on their

need for health-related supports. Additionally, this approach encourages the provision of early, moderate, and crisis intervention efforts based on a child's severity of concerns. Sheridan and Ellis (2006) further stated that the school psychologist should assist by helping to educate health care professionals regarding school concerns, school professionals regarding health care concerns, and families regarding ways they can effectively collaborate with both entities. Pediatric school psychologists are adequately skilled in health issues and could help facilitate this process. Other professionals, such as nurses and social workers would also be of valuable assistance.

Warger (2001) stated that the purpose of full-service schools is to address all concerns affecting the lives of at-risk children. This is typically done by providing services to children with disabilities who typically come from impoverished families and/or who have physical, mental, or learning concerns. This is accomplished by providing easily-accessed services to children when problems are first identified. Blank, Melaville, and Shah (2003) summarized the research on community schools and found significant gains in academic achievement, improved family stability and involvement in their child's school, improved school climate, effective use of school buildings, and increased security and pride in neighborhoods. The concept of full-service schools may be most beneficial in identifying and providing services to younger children and their families who are connected with early childhood centers and daycares. This would promote the earliest and most beneficial prevention, assessment, and intervention effects for young, at-risk children.

The School Psychologist's Role in Developing and Implementing Policy

The current study showed that general pediatricians are best able to follow AAP

guidelines for serving young children having delays when provided with adequate training materials and opportunities, in addition to opportunities for collaboration within and across disciplines. School psychologists can play a key role in assisting this process at its foundation - policy development. To assist with policy development, school psychologists are encouraged to begin initiating discussions with general pediatricians (those practicing and within academia) that would assist both disciplines in understanding each others' perspectives and experiences related to servicing young children. This would be an appropriate time for school psychologists to educate general pediatricians about the expanding role of school psychology, in addition to the vast skills held by these professionals. After developing rapport with the medical community, school psychologists can focus their efforts on assisting with the design and implementation of research that is geared towards solving concerns within both disciplines, as these concerns relate to young children. The goal of having school psychologists assist with research development and implementation would be to provide a more comprehensive view of the problems faced by a variety of stakeholders and possible solutions to these problems, as well as develop plans of action and evaluation. School psychologists' understanding of the change process involving both individuals and larger systems would provide general pediatricians with valuable support as they prepare to develop novel and revised guidelines and initiatives, and methods of accountability that enable their adoption of and adaptation to change. Through this process, school psychologists could support their field as well as the medical field with overcoming barriers and making lasting change. With a firm foundation based on research and inclusive of multiple disciplines and perspectives within disciplines, effective policy development and

implementation will occur.

Implications for Practice

Although this study's focus began with a discussion about general pediatricians, the importance of collaboration among individuals within the child's home, school, and broader community environments must be underscored. The old African proverb states, "It takes a village to raise a child" and as time evolves, this statement continues to hold true. Family life is not as it was fifty years ago, and children and families are currently faced with barriers that are preventing them from receiving the basic necessities of life. With that being said, professionals are and will continue to be challenged with the assignment of collaborating in an effort to assist our most needy children and families. It is imperative that we keep this focus if we truly believe that all children can learn and no child should be left behind. Considering the limited resources and overwhelm experienced by several disciplines, a collaborative effort is necessary. Therefore, healthcare professionals, mental health professionals, early childhood and elementary school educators, rehabilitation specialists, families, and many other stakeholders are equipped with the knowledge and skills needed to positively impact our nation's children. School psychologists are uniquely trained to collaborate with others to address the developmental, learning, mental health, and behavioral concerns of children. The following are a list of general recommendations that each participant within a child's life (other than general pediatricians) can implement to assist with effectively communicating/collaborating with other professionals to serve young children and families in need.

General Recommendations for Parents and Caregivers:

- Ask questions to all professionals about your child's development and current functioning on a regular basis.
- Ask for examples of ways to promote your child's development within the home and/or school settings.
- Keep your child's general pediatrician informed about the evaluations, procedures, and therapies your child has received.

General Recommendations for Other Healthcare Providers and Community-Based Specialists:

- With parent permission, provide updates of recent evaluations, procedures, therapies, etc. that have been completed for the general pediatrician's review.
- Inform parents of ways they can support their child's functioning within the home and/or school environments.

General Recommendations for Educators:

- Keep parents informed about their child's progress within the school setting.
- Inform parents when concerns arise for their child. Also, when these concerns arise, seek counsel from members of your school's or childcare center's problem-solving team first. This will provide the opportunity for conducting assessments and developing appropriate interventions for implementation and monitoring prior to diagnosing a child with a disability.

General Recommendations for School Psychologists:

- With parent permission, update the child's general pediatrician on screenings, evaluations, and/or interventions completed.

- Work with the school’s problem-solving team to address concerns for young children. Also, educate the school staff regarding the implementation of effective problem solving when working with children. This is an important duty for school psychologists, considering the traditional “test and place” role of school psychologists is being replaced by a Response to Intervention (RTI) approach to assessment and intervention.
- Educate parents regarding their rights, expectations for their child, and ways to become involved with their child’s education

As a result of interview data obtained within this study, specific recommendations also have been provided for other healthcare providers and community-based specialists, educators, and school psychologists.

Additional Recommendations for Other Health-Care Providers and Community-Based Specialists:

- Consult and/or inform general pediatricians of concerns that may arise regarding the child’s health or general functioning during visits.
- Conduct developmental, vision, hearing, dental, and/or other screenings within the child’s home or community settings to assist with gathering assessment data for early intervention planning.

Additional Recommendation for Educators:

- Conduct developmental screenings within the school or childcare setting.

Additional Recommendations for School Psychologists:

- Assist with the development and implementation of public screening efforts within the community

- Educate school staff regarding school procedures (e.g., Exceptional Student Education (ESE) guidelines), in addition to assessment and intervention strategies.
- Educate medical professionals on understanding and interpreting reports, using standardized screening tools, and understanding school procedures and the law (e.g., Other Health Impaired category of special education, Section 504 Plan, etc.)
- Work within the school and/or non-traditional settings to assess the developmental functioning of young children and create plans for early intervention.
- Collaborate with other stakeholders to participate in community outreach efforts (e.g., free, public screenings) that help to identify young children having potential delays and disabilities.
- Assist with developing policies in collaboration with general pediatricians and/or other disciplines to promote strategies for the early identification of children having developmental concerns.

Future Research

Regarding the limitations noted within this study, the researcher has developed several recommendations for future research. In an effort to increase generalizability to the larger population of general pediatricians, it is suggested that this study and/or similar research studies utilize a larger sample size of individuals who are members of the AAP. Additionally, in the event that future qualitative studies are conducted, the researcher should first consult with general pediatricians prior to conducting interviews to determine

how they would structure the topic of AAP guidelines and barriers themselves. This may provide even “richer” data that address the specific topics of concern held by general pediatricians. Additionally, after conducting interviews with general pediatricians and allowing them to review transcripts, researchers are encouraged to ask a follow-up question (i.e., “Since the interview, is there anything you would like to add?”). This follow-up question will provide the interviewee an opportunity to share additional information. Finally, face-to-face interviews are recommended instead of phone interviews in order to capture the verbal and nonverbal communication patterns of the interviewees.

Additional recommendations for future research also should be noted.

Specifically, it is suggested that future research examine the feasibility of general pediatricians’ use of developmental screeners within multiple settings. As mentioned previously, general pediatricians who are unsure of or refuse to use these screeners may benefit from observing a colleague or other professional model the administration of them and/or have access to additional personnel (e.g., medical residents, school psychology interns, volunteers, etc.) to help them incorporate the usage of these tools within their environments. The use of computer technology also should be considered to assist with the completion of developmental screeners and the provision of anticipatory guidance during the visit.

Furthermore, an examination of general pediatricians’ characteristics, thought processes, and readiness to adopt change would provide an understanding of the individuals who are most/least resistant to proposed changes (e.g., new policies, guidelines, etc.) and the specific strategies that must be developed to facilitate an

acceptance of change. Regarding children from low SES backgrounds, a pilot study examining the effectiveness of providing alternative methods of receiving medical care for this population of children who often lack access to the medical home should be examined. Also, studies examining the development and implementation of full-service schools/early childhood centers within communities are another area in which continued research would be beneficial. Finally, there is a need for policy research to determine the impact of health-related and health insurance policies on the services and service delivery provided by general pediatricians and other healthcare professionals.

Conclusion

This study sought to determine how general pediatricians have overcome the many barriers faced within their daily settings as they strive to provide services for young children with delays and disabilities. The use of both formal and informal strategies and/or supports by general pediatricians has shown their resilience and dedication to helping children and families. Every professional has or will face barriers within his or her career; therefore, it is necessary to emphasize the benefits of collaboration across disciplines as a method for overcoming those obstacles that cannot be eradicated individually. This study demonstrates how implementing a multidisciplinary, collaborative approach can assist general pediatricians and other professionals with maintaining best practice, overcoming barriers, and ultimately providing the most beneficial early identification and intervention services to at-risk children and their families.

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Appendices

Appendix A

Introductory Email



Dear AAP Member,

You have been selected to participate in a survey after consulting with Drs. Carol Lilly and Lynnette Ringenberg who are both past representatives to the Region V Florida Chapter of the AAP. They have assisted me with identifying pediatricians within the West Florida area who have a reputation for following best practices for serving young children.

Please go to <https://www.surveymonkey.com/s.asp?u=745322426510> to complete a brief (3-5 minute) survey regarding AAP best practices and barriers to implementing these recommendations. Upon your completion of this survey, I will be selecting 7 pediatricians to participate in an interview. My goal is to provide other pediatricians with information on how you have overcome obstacles in identifying children with developmental delays and disabilities. In addition, I would like to collect information on those areas that continue to pose as challenges for pediatricians to follow best practice guidelines.

If you agree to participate in an interview, it would be my goal to gain insight into the practices you've implemented while identifying and referring young children with developmental delays and disabilities, as well as discover what has helped you become successful when working with this population. This interview will take approximately 1

Appendix A (Continued)

hour and will be audiotaped to ensure the correct transcription of responses.

Additionally, I would like to meet briefly with each interviewee at a later date to make certain that my summarization and interpretation of responses is accurate. Restaurant gift certificates will be provided to the 7 pediatricians at the culmination of their interviews.

You are free to contact either myself or my doctoral chair, Kathy Bradley-Klug, Ph.D., with any questions or comments. You can reach Dr. Bradley-Klug at (813) 974-9486 or kbradley@tempest.coedu.usf.edu. I thank you in advance for taking time out of your busy schedule to assist me with my research.

Kahlila Mack, Ed.S.
Doctoral Candidate
University of South Florida

Note: All survey and interview results will remain confidential and there will be no identifying information published with the results.

Appendix B

Follow-up Email



Dear AAP Member,

To those who have already completed the survey, thank you very much for your feedback. If you have not completed the survey, please take a few minutes in the next few days to complete it. I greatly appreciate your feedback.

Here is the information about the survey:

Please go to <https://www.surveymonkey.com/s.asp?u=745322426510> to complete a brief (3-5 minute) survey regarding AAP best practices and barriers to implementing these recommendations. Upon your completion of this survey, I will be selecting 7 pediatricians to participate in an interview. My goal is to provide other pediatricians with information on how you have overcome obstacles in identifying children with developmental delays and disabilities. In addition, I would like to collect information on those areas that continue to pose as challenges for pediatricians to follow best practice guidelines.

This interview will take approximately 1 hour and will be audiotaped to ensure the correct transcription of responses. Additionally, I would like to meet briefly with each interviewee at a later date to make certain that my summarization and interpretation of responses is accurate. Restaurant gift certificates will be provided to each of the 7 pediatricians at the end of their individual interviews.

Appendix B (Continued)

You are free to contact either myself or my doctoral chair, Kathy Bradley-Klug, Ph.D., with any questions or comments. You can reach Dr. Bradley-Klug at (813) 974-9486 or kbradley@tempest.coedu.usf.edu. I thank you in advance for taking time out of your busy schedule to assist me with my research.

Kahlila Mack, Ed.S.
Doctoral Candidate
University of South Florida

Note: All survey and interview results will remain confidential and there will be no identifying information published with the results.

Appendix C

Informed Consent Document

This Study: The present research study will be examining the experiences of general pediatricians who have been recommended as successful in following the American Academy of Pediatrics (AAP) guidelines for practice when identifying and promptly referring young children with developmental delays and disabilities. You have been chosen as an interview candidate by the researcher, with the assistance of Drs. Carol Lilly and Lynnette Ringenberg who are both past representatives to the Region V Florida Chapter of the AAP. They have assisted the researcher with identifying pediatricians within the West Florida area who have a reputation for following best practices for serving young children. It is this researcher's goal to discuss with you how you have overcome some of the barriers faced by general pediatricians working with young children, as well as those barriers that continue to exist, despite your efforts. This information will be compiled and used to add to the literature involving successful practice strategies implemented in concordance with AAP guidelines.

Voluntary Participation: Your participation is completely voluntary, therefore giving you the right to withdraw from the study at any time or not to participate at all. By signing this informed consent document from the Institutional Review Board (IRB) of the University of South Florida, you are agreeing to participate in this research.

Risks: There are no known risks as a result of participating in this study.

Benefits: By taking part in this study, you will increase the knowledge base of the pediatric and other child-related fields regarding pediatricians' successful engagement in identifying and referring children with developmental delays and disabilities.

Appendix C (Continued)

Additionally, this knowledge you provide will assist the field with considering ways in which other professionals may collaborate with general pediatricians in an effort to eliminate the barriers faced.

Payment: You will be given a gift certificate in the amount of \$30.00 to a restaurant in the West Florida area upon completion of the interview with the researcher.

Confidentiality of Your Responses: Authorized research personnel, employees of the Department of Health and Human Services, and the USF Institutional Review Board and its staff and any other individuals acting on behalf of USF may inspect the records from this research project. Your individual responses will not be shared with school system personnel, healthcare personnel, or anyone other than Dr. Kathy Bradley-Klug, my major professor. Your interview transcript will be assigned a code number to protect the confidentiality of your responses and will be kept in a locked file cabinet.

What I'll Do With Your Responses: The results of this study may be published. However, the data obtained from you will be summarized and/or combined with data from other individuals in the publication. The published results will not include your name, email, or any other personally identifying information.

Questions? If you have any questions about this study, please call my major professor, Kathy Bradley-Klug, Ph.D. at 813-974-9486. If you have any questions about your rights as a person who is taking part in a research study, you may contact a member of the IRB Division of Research Integrity and Compliance at the University of South Florida at 813-974-5638. I thank you in advance for your participation.

Appendix C (Continued)

Signature of Participant: _____ *Date:* _____

Appendix D

Online Survey

Survey website: <https://www.surveymonkey.com/s.asp?u=745322426510>

Note: Items marked “*” indicate a choice is needed to complete the online survey

Young Children With Delays and Disabilities

This survey will take 3-5 minutes of your time. All responses will be sent over a secure, encrypted internet connection. Additionally, your responses will be compiled with other pediatricians' responses, therefore, protecting your confidentiality.

Demographic Information

Any identifying information that you provide will be protected and ONLY viewed by the researcher.

1. Name (will not be revealed in analysis)

- * 2. Email address (please type the address this survey was sent to)

- 3.

21-31 years	32-42 years	43-53 years	54-64 years	65-75 years	76 years and older
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Gender

Male	Female
<input type="radio"/>	<input type="radio"/>

- * 5. Type of pediatrician

general pediatrician	pediatric subspecialist
<input type="radio"/>	<input type="radio"/>

Appendix D (Continued)

6. Years in practice (check one)

- 1-5 years 5-10 years 10-15 years 15-20 years 20 years or
more

7. Practice Setting (check one) Age

- Hospital
 Private Practice
 Clinic
 Suburban

8. Practice Setting (check one)

- Urban
 Rural
 Suburban

9. Approximately how many hours do you work per week? (check one)

- 30-40 40-50 50-60 60-70 70 or more

American Academy of Pediatrics (AAP) Recommendations

Please note the PERCENTAGE OF TIME per week you have implemented each of the following AAP recommendations for the majority of your patients.

If you have not implemented a recommendation, please note N/A as your response.

Note: Each drop down menu on the online survey has the following options: N/A; 1-20%; 21-40%; 41-60%; 61-80%; 81-100%

* 1. I have maintained and updated my knowledge about developmental issues, risk factors, screening techniques, and community resources to assist with consultation, referral, and intervention.

* 2. I have acquired the skills needed to administer and interpret valid and reliable developmental screeners (e.g., Denver, Ages & Stages, etc.).

Appendix D (continued)

* 3. I have presented screening results to families using a culturally sensitive and family-centered approach.

* 4. I have referred children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community.

* 5. I have determined the cause of delays or consulted with the appropriate individual for determination.

* 6. I have maintained relationships with community-based resources and coordinated care with them through the medical home.

* 7. I have increased parents' awareness of developmental disabilities and resources for intervention.

* 8. I have offered guidance to families by interpreting consultants' findings.

American Academy of Pediatrics (AAP) Recommendations...continued

For the following recommendation, INDICATE YES OR NO.

* 1. I have developed a strategy for providing periodic screening in the content of office-based primary care.

Common Barriers to AAP Recommendations

Please identify the barriers that you have been able to overcome at any time within your practice. Please CHECK ALL THAT APPLY.

Appendix D (Continued)

- * 1. My office staff is currently able to...
- obtain reimbursement for preventive services
- administer validated screening tools
- score validated screening tools
- refer families to c Appendix D (continued)
- assist with developmental surveillance
- budget for the cost of standardized instruments

Interview

You may be chosen to participate in a face-to-face interview. In the event that this occurs, please indicate possible days and times (including non-patient or administrative days) that this would be most feasible.

- * 1. Best day(s) of the week for possible interview contact (check all that apply)

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday
- Saturday
- Sunday

- * 2. Best time of the day for possible interview contact (check all that apply)

- | | | |
|-----------------------|-----------------------|-----------------------|
| Morning | Afternoon | Evening |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

You have reached the end of the survey. Thank you for your time.

Appendix E

Interview Protocol

Participant # _____

“Thank you for volunteering to participate in this research study today. The purpose of this interview is to help me understand the experiences that you have had within your practice when identifying young children with developmental delays and disabilities early, and referring these children to early intervention services. Specifically, I am interested in knowing how you have been able to consistently follow some of American Academy of Pediatrics’ recommended practices when working with young children. The results of this study will potentially help other physicians learn strategies that you have implemented to overcome some of the common barriers faced by general pediatricians (e.g., lacking knowledge/training in the administration and scoring of validated screening tools, lacking knowledge of community resources for intervention services, etc.).

Additionally, the field of school psychology will be informed regarding ways to collaborate with general pediatricians in an effort to provide children with the best start to their early educational years. You have been selected for participation in this study because you have demonstrated success in following AAP’s best practices within your practice.”

“Your story will be recorded in order for me to review at a later time to ensure that I am capturing what you are sharing in an accurate and representative manner. Keep in mind that there are no right or wrong answers; I am simply hoping to learn more about your experiences, particularly those related to overcoming barriers within your practice when

Appendix E (Continued)

engaging in identification and referral activities of young children with developmental concerns.”

“Before we begin, let’s set a few ground rules. This interview will last up to 60 minutes. We will really try to respect these time limits considering your busy schedule. Also, I will be speaking as little as possible, in an effort of focusing on prompting you for more information and clarification as you tell your experiences and perceptions. If at any time you feel uncomfortable, please inform me and we can move to the next question. Finally, on a later date I will be requesting a follow-up meeting with you to review your responses and ensure their accuracy. Do you have any questions or concerns at this time? Ok, let’s begin.”

“Please tell me about your story and experiences as a pediatrician at name of practice.”

The researcher will use a combination of clarification and paraphrasing in order to ensure the accurate understanding of the pediatrician’s story. In addition to asking the primary research question, the researcher will ask the parent an open-ended follow-up question about topics specified below. For each area, the researcher will ask:

“Tell me more about _____”

or

“There are a couple of other things I was wondering about. Tell me more about _____”

Appendix E (Continued)

Interview Topic Domains and Prompts

Question 1 “You indicated on the online survey that you have been able to consistently maintain educated about developmental issues, risk factors, screening techniques, and community resources to assist with consultation, referral, and intervention.”

-“The first is child developmental issues. Tell me more about how you have been able to do this.

-The second is child risk factors. Tell me more about how you have been able to do this.”

-The third is screening techniques. Tell me more about how you have been able to do this.”

-The fourth is knowledge of community resources to assist with consultation, referral, and intervention. Tell me more about how you have been able to do this.”

Question 2 “You indicated that you have acquired the skills needed to administer and interpret valid and reliable developmental screeners. Tell me more about how you have been able to acquire these skills.”

Question 3 “You indicated that you have been able to develop a strategy for providing periodic screening in the context of office-based primary care. What strategy have you developed? How did you develop this strategy?”

Question 4 “You indicated that you present screening results to families using a culturally sensitive and family-centered approach. Please provide an example of how

Appendix E (Continued)

you have provided this information effectively.”

Probe: “For example, what is you have a mother who is minimally competent in English? What do you do?”

Question 5 “You indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community. Please explain the process you have implemented in order to do this in a timely fashion. What are the steps you take from well-child visit to referral? How did you become knowledgeable of the programs within the community?”

Question 6 “You indicated that you are able to determine the cause of delays or consult with the appropriate consultant for determination. Please provide an example of how you are able to connect with other healthcare professionals/consultants regarding your patients.”

Question 7 “You indicated that you have been able to maintain relationships with community-based resources and coordinate care with them through the medical home. How have you been able to do this?”

Question 8 “You indicated that you have been able to increase parents’ awareness of developmental disabilities and resources for intervention. Please explain how you have been able to do this within your practice.”

Question 9 “You indicated that you have been able to assist families with interpreting reports or feedback from other practitioners. Please explain how you make this happen.”

NOTE: For each AAP recommendation not endorsed by the general pediatrician, the

Appendix E (Continued)

researcher will state the following:

“I noticed that you did not indicate that you have been able to...”. Please explain your views on why this is the case.”

Question 10 “I am going to read through a list of barriers and I want you to either inform me that the item is a barrier you have yet to overcome, or explain how you have managed to overcome the barrier.”

- a. Obtain reimbursement for preventive services
- b. Administer validated screening tools (e.g., direct assessment or parent report)
- c. Score validated screening tools
- d. Refer families to community resources for intervention
- e. Assign office staff to assist with developmental surveillance
- f. Finance the cost of standardized instruments

Follow-up Question: “Are there any other barriers you encounter?”

Probe: “How have you addressed these barriers?”

Question 11 “The final question regards your contact with other professionals who work with children having developmental delays and disabilities. Which professionals do you refer to when you identify a child? Can you/do you collaborate with other professionals?”

Appendix F

Request to Review Transcript

Dear _____,

On _____, I conducted an interview with you regarding your experiences working with children having developmental delays and disabilities. At that time, we discussed your experiences with implementing AAP guidelines and your views on existing barriers.

Attached to this email is the transcript from your interview. As explained to you at the time of the interview, your transcript does not include any identifying information.

I am asking that you take a few minutes of your time to review this attachment to determine if the interview was accurately transcribed. Please send a reply email informing me of any changes that are needed. You may provide comments on changes within the reply email. **Please respond with your feedback via email by _____.** I

will be in contact with you in the near future to review my study's results as I am preparing to defend my dissertation this summer. Again, I thank you for your assistance and time.

Best regards,

Kahlila Mack, Ed.S.
School Psychology Doctoral Candidate
University of South Florida

Appendix G

Transcripts

Participant Number: 1

Interview Date: 3/21/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset.

I'm going to be referring a lot to the online survey that you filled out. Question one...you indicated in the survey that you have been able to keep up to date about developmental issues, risk factors, screening techniques, community issues, etc. Let me ask you first...when talking about child development issues, how have you been able to increase your knowledge about that topic?

I think one way is to...I have a special interest in children with special needs so I have in national meetings, C.M.E.s. I might attend some of the workshops and lectures related to special needs like ADHD, children with disabilities, and stuff like that. As far as resources, the other resources would be through the AAP. It's more like, it's the kind of information that I don't seek out - it finds me. For example, I am a member of the Council on Children with Disabilities with the AAP, so I'm on their listserv. So I might not go into depth on everything they send, but sometimes they send a listserv which might talk about a certain guideline. And if it's something of interest, I might look more into it. Otherwise, I might just scan it. So, the listserv might be helpful as you can pick and choose what you would like to go more deep into.

Local resources sometimes are very hard. I find it challenging to know what resources are out there. Sometimes we know what is available in our own backyard at USF or

Appendix G (Continued)

Early Steps. Once the kids are over that age and not yet in school, or even sometimes when they are in school, it might take a while to get the children in the system. It might take a few months before parents are aware of what's out there. So, it's sometimes hard to find what is available even local.

You're talking about community resources?

Yes, community resources.

Ok, so, are you saying that you have it under control when it comes to the resources affiliated with USF or Early Steps, but it becomes a little more difficult to access resources outside of those?

Yes... and I think, you know, the national guidelines, because I don't practice development I don't consider myself an expert in applying them. It's just that, some of them I have more experience with applying them because some of them I know more about because of the volume of patients that I see. For example, the ADHD toolkit that the AAP came up with - I use a lot. But, some of the more sophisticated developmental testing that Early Steps does, I might be familiar with the test itself but we don't really use them.

You're actually hitting on a question regarding screening techniques. How would you say that you've increased your knowledge about the different screening techniques...through the same methods that you mentioned to me or other methods?

Appendix G (Continued)

Yes, and I think these are mostly the only methods. As for the screening techniques, I don't think I've had more opportunity to do them. I'm not too far up to date on new things because, like I said, we don't practice using them. If I were in the community where there were no Early Steps, I would have to use it more and I'd be more familiar. Those are the things you end up referring.

Alright. The second question is...you stated that you gained the skills needed to administer and interpret reliable developmental screeners. Is that related to the information we just reviewed? How did you acquire this information? How did you learn the skills to administer and/or interpret the tools that you use?

I think that I was referring to the ADHD toolkit. Some of the AAP guidelines that were created, they came up with new guidelines on autism and stuff like that. I would say more like the diagnoses are based on diagnostic criteria for autism, rather than doing the actual testing myself. Like, we administer the Ages and Stages questionnaires. We administer some of the developmental questions based on the Denver screening. So, those were acquired during residency. We used to use the Denver at that time and now the Ages and Stages became more popular – it's easier.

So the Ages and Stages is one questionnaire that you use, and the Denver is not?

Yes – the Ages and Stages. The Denver, we don't use it anymore. We have our preprinted sheets in the clinic for well visits and there is a section on development that has the questions, does your child smile, does your child roll over, these questions were actually developed from the Denver. Our sheets are aged-based, so if I'm seeing a patient

Appendix G (Continued)

who is on a six month old visit, we have a sheet with developmental questions on that six month old sheet which are based on what a six month old should do based on the Denver. So even though it's not a formal Denver assessment, it has screening questions and if somebody fails, or, mom says, yeah he does all the motor stuff but not the language stuff, then you worry that maybe the child needs to be referred to speech so they can work with you and your child.

Also, most of our questions, actually all of our questions are between parentheses. For example, does your child say baba and dada, has an L in between which tells us that it is for language so at least we can make sure, visually, if the child fails like five out of fifteen questions. You can see visually that most of the five are clustered into fine motor so we would seek occupational therapy.

Is there some kind of a formula or criteria set in addition to using clinical judgment?

You mean like whether a child needs to fail a certain amount before referring?

Yes.

I think it's more of a judgment call because sometimes it depends on the child's age because it is a spectrum so if the sheets say a six month old should do this but everything else being normal, maybe, for example, you have a mom who was worried because her child doesn't speak, she doesn't say words, and based on the sheet, she is supposed to. Then as you dig more into it, everything else shows that she is really developmentally fine –actually more advanced. So, it was more because she's actually getting so much

Appendix G (Continued)

attention that she doesn't need to ask for anything she needs. Before she points to anything she's getting it. So, it actually wasn't a lack of stimulation but it was too much babying that, we actually explained to mom that if you give it to her she can say doll and let her repeat. We said we would wait a few more months to see. So, sometimes it's not an automatic referral. It's really individualized by the child.

I understand.

Like, if you have a premie baby and sometimes people forget that they were born premie because they're now six months old. So technically, if they are still two months behind on doing things yet everything else is still progressing, the little gap could be just because they are premature...and sometimes people forget that also. So, when we say this patient or this kid is ok on everything but she doesn't do this, then we go to the questions. If everything else is fine, for example, she was not a premie, we put them in a different category and then we would give them a chance, given the benefit of the doubt.

So, since we're on that topic, I'm just going to jump ahead. Help me visualize what a well-child visit would look like from the moment they come in. I know everyone is different, but what kinds of things would you consider constants? You know, from when they [patients] come in to the point when they may be referred for services outside of your care.

Well, during the well-child visits in our setting, usually the residents go see the patients first, and our sheets are actually designed so they have the same kind of trigger. So, they

Appendix G (Continued)

start with what we call an interval history. You know...has anything happened since we've last seen you? We saw your baby two months ago... anything in between? Was he in the hospital? Was he sick? So, that's the interval history. After that, we go over what we call the health maintenance, including questions on diet, elimination, how much they sleep, who lives at home, social...you know, almost like screening questions. Then there are the developmental questions where we talk about the milestones. Then the residents do a full physical exam. Then, based on the history, the physical, the other side of the sheet is what we call anticipatory guidance also with age specific topics on each sheet that gives the residents an idea of things to discuss at that age. So, if they're seeing a two month old, the stuff that's going to be on top would be talking more about fever, talking about taking the temperature, remembering to talk about, maybe sleep and stuff like that. If they are seeing a six month old or nine month old, there would be more safety stuff. You know, talking about child proofing the house because the child is mobile and stuff like that. And then, after that we would talk about shots if they need shots and things.

Now, if at any point they need a referral for one reason or another, if they have developmental problems, usually the referral will happen that day. They [parents] get the referral, and it also depends on the age. If they are less than three years old, then they qualify to go to the Early Steps at least 1 visit – the initial visit. So, we write the referral and the parents bring it to the front desk. At the front desk based on, I think, if they are less than two years old they actually send them to Early Steps. If they are older, then it becomes based on, if we're not doing it through the school, Speech or PT or something

Appendix G (Continued)

like that, then we would work through their insurance and see if, for example, they have Medicaid, where would they go. They would give them a list or a phone number to call. Occasionally, we have pressing time where you want this kid seen... it's the first time we've seen them, they are really behind, and they can't afford to wait another three months for an appointment. Then we might end up making a phone call for them and we've tried to get our social workers to facilitate that.

Now if they have more global delays, like if the physical exam is abnormal, they may actually qualify for CMS – Children's Medical Services – because if they have cerebral palsy, for example, then we would actually use the social worker to get that done through the CMS system and get a caseworker who would actually help the family. Most of the time, those kids will need more than one referral. They would need to see neurology, and other people, so the CMS worker would help them through that.

You mentioned the Ages and Stages. Tell me how your staff have been able to acquire the skills needed to administer and interpret this tool, as well as any other ones.

The Vanderbilt?

Yes how have you and your staff done this?

We use the Vanderbilt assessment for ADHD. We used to use the Conners' scales and actually I think the Genesis Clinic still has the Conners' that they use sometimes. Here we have the Vanderbilt partly because it was an AAP endorsed initiative when they did the ADHD toolkit and that was how we learned it actually...it was for the ADHD toolkit.

Appendix G (Continued)

We actually ended up going with the Vanderbilt because it was not copyrighted. So, we actually revised it on form and copied it...versus the Conners'. We would have to buy them and pay for the actual triplicates and it's a little bit harder to score.

Now the Conners', I learned it through my residency because that's what we used to do during residency. The Ages and Stages, it was not very common during my residency. I ended up learning it though, with [doctor], one of the developmental specialists. For work sometimes with [doctor], she was more based at All Children's and she was doing a project on the Ages and Stages for the residents. While the residents were doing their rotations they would learn it but they wouldn't apply it in clinic. They would learn it in the developmental rotations, but when they went to the clinic, partly because we didn't know it, the faculty did not know it, and it was not part of what we do during the well visit because we had questions from the Denver that was part of our screening. So she was testing to see if the residents applied it in their clinics. For example, would they catch things earlier? So, she was reviewing charts afterwards to see how many referrals they made based on the Ages and Stages. Actually, now it's becoming more popular but we only target certain age groups.

What age groups?

We started out with the six months, nine months, and twelve months but I think we expanded it to the eighteen months. So, it's six to eighteen I guess now. So basically we know what it entails, but the residents learned it on developmental rotation. But really, the Ages and Stages is the easier one because it is more parent-driven. You don't have to

Appendix G (Continued)

do a whole lot better than looking at the data and interpreting it. So, we do the Denver for development which is part of our forms, our history forms, and we do the Ages and Stages for certain age groups, and for ADHD we use the Vanderbilt.

When it comes to actually using these in the clinic, what issues have you found that have interfered with the flow?

For the Vanderbilt, we give them the questionnaire and they take it home. There's a teacher and parent questionnaire, but for the Ages and Stages we had to figure out where to fit it in that flow in the clinic. The best thing that was decided was that when the parents signed in, most of the time there is always a waiting time after they go to the front desk before the nurse calls them. So, while they are waiting in the waiting room they will start filling that out. But still, sometimes it may extend the visit a little because many times parents are called and they're not ready yet. They haven't finished filling it out. So, sometimes they would finish it when the residents go to another room after seeing the baby, they will finish it and then we'll look at it. So, even looking at it is another extra time. So, definitely that and having the staff remember which ages to put in the charts. Sometimes the first few weeks, we didn't catch it and we forgot to put those forms in the chart.

So, interpretation...it happens when?

Now, interpretation happens towards the end with the resident after they staff. Sometimes maybe the child is waiting for the nurse to come give their shots and at that time the residents are looking at it with us and deciding if the kid needs a referral.

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Majority of kids are fine and rarely need it so usually it doesn't extend things too much. But then the ones who need it, it does because you think you're done and all of a sudden you realize that the kid needs this. That happens pretty much with a lot of other things, like if you find the kid has bad vision. By the time the nurse does the vision and then comes back and says, you know this kid is 20/70 on their vision, then they'll write the referral and it takes a little time. But, I think the key is finding a time that's already within that time, like the waiting room...to have the parents do it...finding the time in that without adding additional time to the day.

My next question actually hits on this. On the survey you indicated that you've been able to develop a strategy for providing periodic screening. We talked about the forms that you use and the modified Denver. Do you think I would be able to get a copy of any of these forms?

Sure, absolutely.

Ok, thank you. On the next one, you indicated that you present screening results to families using a culturally sensitive and family centered approach. Can you give an example of how you provided this information to families?

Sure. Well, most of the time if we, for example, let's say for the kid who needed more stimulation to talk...one is giving them examples. If the kid is behind on speech and needed some more reading time or book time, we participate in the Reach Out and Read program. So, from six months on, we have books through a grant that we basically provide to the kid at the end of the visit to encourage parents to read to their kid. Each

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upper grade book we have in Spanish so the kids who are from Hispanic backgrounds also read in that language. We also, for older kids over five, we have a box that faculty bring used books for the kids because the grant doesn't cover over five years. Also, we have volunteers through the Reach Out and Read program. They are high school students who actually, while the kids are in the waiting room, will actually sit and read for them and demonstrate to the family sometimes, just to role model for them.

Now, as far as if a child has developmental problems and we need to refer and have to present those...most of the time some of those kid's parents may not really suspect it but they have other kids and realize that their child was able to walk earlier or was talking by now. Or, they might bring it up anyway so they might be suspecting something. We may say, "Yes, you're absolutely right. It looks like he or she should be doing more". If it's something mild that they can work with at home, we just give them examples of what they can do or handouts by saying, "Here's some other ways you can stimulate them more." But if they're really delayed and they need to be referred, we basically explain to them what Early Steps is and they get to see a doctor and physical therapist or speech. Sometimes, depending on the parent's reactions, like if they feel that it is one more thing they must do, sometimes I reassure them by telling them to go for the first visit because they may evaluate their child and decide that he's ok. Or, they might need a few times a week therapy, but you don't need to come to the center. We can teach you what to do at home. So, I reassure them and encourage them to go to the first evaluation so they don't neglect their appointment. I say that it might be just a one time thing or you might need

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to take your child a couple of times a week for therapy. Or, if your child's in a school, they might do their initial assessment and they might recommend that the therapist in the school does the therapy two times per week. So it's usually through handouts, examples, demonstrations, etc.

Ok...and how about if it's an individual who has a language barrier? How do you present results to them?

Depending on if they're Spanish, usually the residents have one-half day a week in clinic. So, what we try to do is have at least everyday one resident who speaks Spanish so there is somebody there that speaks Spanish. Now if it's something totally...like Japanese or whatever, sometimes we've used staff if there's anybody who speaks those languages. We've also used AT&T translation on the phone. That's usually it. We have some Creole and mostly Hispanic.

Another question is that you indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention or early childhood programs within the community. Can you explain that process to me, although some of it may be redundant?

If there's an issue where we've discovered that a kid needs to be referred, we write the referral that day and then bring it to the front desk, and the front desk, based on their insurance would actually direct them to the place to go. Most of the time they would give the parents a phone number to call and make the appointment. And we actually fax the referral to that place.

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I usually tell the families, if they're child is a school aged-child, that I know that different schools have different waiting lists. So I would say, if a child needs IQ testing or psychological testing, I usually write it on a prescription. So it's not a referral form. But, they can take it to the school and have them try to schedule the child. If the child's really delayed and needs help immediately, I would say that if they [parent] find out that it's going to be more than a month or two, just come back because we might have other community resources or we'll send you for one time to [doctor] and then the school can pick up later. So sometimes it's empowering the family to go to the school because it's an entitlement...the child is entitled to it. But if it's going to be five months before your school tests him, we can maybe help you call the school. Sometimes we've done that where the social worker follows up with the school and asks if the child can be moved up a little bit. But if we can't go anywhere, I would say come back and don't wait the five months because if we don't see you until later you're child will need more help. We try to say if it is beyond a certain amount of time that we'll give the family, usually I tell them, six to eight weeks which is a reasonable time. If it's more than that I would say to come back and we could look at other resources.

So you're saying from the moment you notice something is not quite right, a referral is made and you guys would even call and try to expedite the process?

Yes, we try to expedite the process.

Ok.

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And depending on the urgency of it, absolutely. Definitely, like if we run into behavioral problems. For example, we had a kid last week who, I think he was diagnosed with ADHD, but also he started having violent behavior – kicking the teacher, kicking the mom, people were scared of him at school and he was a little kid...seven years old. And mom called so many times, I mean like, communication with mom everyday. Because we would give her like, “try this” and she’d call back and say she called the psychologist’s number and the psychiatrist’s number that we gave her and they can’t see him. The earliest they can see him is in a month and she can’t really do that. So we had the social worker call for her. So definitely, depending on the urgency, we try to expedite the process.

Ok. You also indicated that you are able to determine the cause of delays or consult with the appropriate healthcare professional or another consultant to help you determine that. In general, what do you do to determine the cause of delays? Or, since we’ve talked about that twice already [laughing], how do you determine when you need to consult with another healthcare professional or another person?

Sure, I think for the most part, as long as I don’t think the delay is something coming because of prematurity or being a normal type of...well, usually a delay is not normal but if the child is otherwise normal and has been gaining milestones, but for one reason or another they’re a little bit behind but actually making headway and I found a reason like maybe mom was not paying attention to him or he is with the babysitter and he’s left oftentimes laying down do he doesn’t really get enough motor stimulation or something to fix, then I might not consult initially with someone. I might try some of the

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suggestions that I talked about, like giving her handouts or examples of some things to do. Now, if she tried that and it didn't work, or the child has other, maybe neurological problems like the physical exam is abnormal, the kid's not cognitively appropriate, it looks like he may be a little retarded or looks like the child has some syndrome, all of those we definitely have referred most of the time. I even would refer to development like [doctor] for more of the normal stuff. But when it becomes abnormal, we require more than just [doctor]. Like maybe neurology or genetics or other specialists to be involved. So, sometimes mostly I guess we're going back to how severe the delay is to determine going to a specialist and whether there are any associated abnormalities that could be contributing to the delay. So the delay is there but is everything else normal or are there other neurological problems, genetics, or dysmorphic problems?

So, in these situations have you found yourself consulting with these people or just referring on so that they can now take the steps to manage?

Most of the time we refer so we can allow them to manage at the same time. But, we are still their primary, so most of these consultants we refer to keep us informed by sending us copies of the visit. Some of them especially in the case of neurological problems, they need more than a one time visit and most of the time it may not be fixed. They may be started on some seizure medication or something. For those, we usually want the neurologist to keep monitoring, or the psychiatrist, especially if medication is involved.

Speaking of consulting with others, have you ever consulted with individuals within the school system on the behalf of a child? If so, with who and how has this been

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done?

Yeah, the only thing I can think of is more for ADHD or more for, if we're trying to advocate for a child to get tested through the school system for a disability more than like developmental delays. It's more for behavior or stuff like that.

If we think that maybe there are some modifications that the school or teacher could do, or sometimes we get a note from the teacher that says that this kid needs to be tested or whatever. So we call back to say, "What do you mean, give us an example" because sometimes some modifications for some ADHD kids, like putting them in front of the classroom to keep their attention, you know, things like that we may request that the teacher do. The other thing, for testing, if the child needs to be tested and the delay is long, sometimes I might get the social worker...our social worker is really good. He even goes to the school and a couple of times he even stays in the class to see what...like if it was disruptive behavior...he would watch what happens to help the family and teachers.

So, you're saying the social worker would even go to the school or you may sometimes get a call from a teacher talking about certain issues...

The teacher would send a note with the parent.

Are there any other people in the school system that you've had any experience with regarding a student?

No.

Ok. You have access to a social worker, do you have access to other professionals

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here at your clinic?

No, I wish we had a nutritionist, but we don't. We have a social worker in the same building. CMS is here so some of the case workers for some of the children with special needs and some of the children with chronic diseases who are actually CMS patients, usually some of the guys upstairs are actually the caseworkers. So, we request their help sometimes for assistance with their patients.

I understand. We have a couple more. You indicated that you've been able to maintain relationships with community based resources and coordinate with them through the medical home. Give me some feedback on how you've been able to do this.

I think one is through our social worker going to the school and advocating for testing a child or providing therapy. The other thing, I think of Early Steps as the community resource that we use a lot because, hopefully we can pick those patients up before they're three years old. Hopefully we don't miss the boat on them and most of those kids actually get referred first through Early Steps. That's mostly our connection to community resources.

I guess the other one that we use sometimes is...occasionally we have behavioral problems other than ADHD. Or, it could be ADHD confounded with something else.

You know, conduct or oppositional defiant, or aggressive behavior. We might establish that there might be based on the social history, maybe let's say there was a divorce in the family or other stressors that maybe the kid and the family might benefit from therapy.

So we send them to some of the mental health agencies in the community. Like that kid

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whose mom called, we had originally given her the number to the Crisis Center so if she was really in a bind. The other thing that we use sometimes depending on the insurance, sometimes we use some of the USF mental health if they are on their plan. We have a lot of our patients on Medicaid so we are forced to send them to certain places rather than others.

Ok. You also indicated that you have been able to increase parents' awareness of developmental disabilities and delays and resources for intervention. We might have touched on it a little bit but tell me how you've increased their awareness.

When we find a disability in a child, we talk to them about the different options and therapies. In cases of ADHD, we give them a lot of handouts on behavioral management and information on books for parents to read about ADHD, like a list of books and ADHD websites.

We also talk about, like if a child turns out to have certain developmental problems because of a syndrome. For example, Downs Syndrome, we...hopefully not just us...and maybe the genetics people would talk to them more about some resources in the community to help them understand more about it. So it's really more through verbal education or tangible things like handouts or websites.

You also indicated that you've been able to assist families by interpreting reports or feedback from other practitioners. Let's say you get a report from...or your patient brings in a report from the neurologist or someone. How do you go about handling that situation?

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We go over it with them, like especially when the testing happens in the school and we get back the report with all the scores like the verbal score, assessment score, and usually there is an impression and usually they want to know what it means. So, we go over it with them. Same thing like I said with ADHD. When we give them the Vanderbilt, usually we don't give them any medication the first time. We say we need to evaluate your child and get the feedback from the teacher and parent so bring those back...so when we score them we go over it with them. We say, based on those scores, your child does not meet the criteria for ADHD. Yes, probably he or she is disruptive in school but let's find out why. Otherwise, send him to the psychologist. Maybe there are IQ problems. So, basically by looking at them again we would set another appointment to go over those. But that's if they bring the report themselves. Now, sometimes the report will come to us and the child is not scheduled for a visit. Usually those reports come to the nurse, the nurses pull the file chart, and any outside communication for the residents and doctors in the acute clinic. They go through them and have to sign off on it. But, it does not need follow up...it just gets filed. The next time the child comes, whoever sees them will review the chart. If the next appointment is next week, then the report will be left alone and filed and the person may receive a note to review the report. Or, it's explained to them over the phone that they will need to come in to discuss this.

If there's something in the report that you don't understand, what do you do?

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Sometimes we call the person who sent the report. Sometimes we might call the family to see if they are scheduled to see the neurologist again. Then, we'd ask them to get the information from the neurologist because if they have questions, we can't answer them anyway. We encourage them to discuss it with them and encourage the family to write questions down before going to the next appointment.

Ok. This is the last question I have for you. I'm going to read through a list of barriers that are in the literature. First, I'm going to start with the things you stated that you and your practice have been able to overcome. Then, I'm going to ask you why you think some of the other barriers still exist.

You indicated that you've been able to score validated screening tools – so this is not a barrier for you. Tell me a little about why this is not a barrier. We talked about the residency students being apart of the process, so they helped out a lot.

Right.

Is there anything else that has helped this not become a barrier?

We get better at it as we do it. Like I said, maybe we've figured out a way in the process...when to do it in the visit...finding a good time so it's not really an additional time. Putting it somewhere in the visit where there is dead time or downtime to really fill it. I think what also helps is having the residents, other than the fact that they already know how to do it, it is also a time while the patients are waiting for the nurse, etc., so residents can do that stuff. So, there's good time management.

The other one that you said is not a barrier is referring families to community

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resources for intervention. We talked about the social worker being very key in this process along with Early Steps.

Yes, that we have a connection with the university and Early Steps and [doctor] is really part of our USF position so it makes it a little easier.

“The other four that you didn’t mention, I want to get your feedback on why they are still an issue. The first one is providing reimbursement for preventive services – why is this a barrier?”

Because sometimes if a child doesn’t have the right funding and even if you’ve established that this is the right place to go for therapy, if that place doesn’t get reimbursed for what they do, they’re not going to take that child. And the parent might not want to pay out of pocket. It might be very expensive for them to pay out of pocket so basically they end up not going. Or, it could be a barrier to us because we figure that we don’t want the parents to end up with the bill and there’s no other place to send them so we’re stuck. Just because insurance X doesn’t have that therapy in place on their plan and it’s the only therapy place available in our area, let’s say, it becomes a barrier to providing them preventive service.

Sometimes it becomes very hard and I think that’s why our social worker helps because it becomes very time consuming to try to search and find...it’s like where do you begin to find...you have to start calling every single place and ask if they take Medicaid.

Sometimes I try to put a little bit of the responsibility on the insurance company by having the family tell the insurance company that their doctor said they need to see this

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specialist...give me a number. Now, if they say there's no body on the plan, then it becomes an issue – definitely a big barrier. Because either you have to try to appeal to the insurance company which really becomes more time consuming for everybody and it might not work. So, I think reimbursement is a big thing.

The other thing that ties into reimbursement is if you don't have better resources in the community and if you know how to do it yourself, it's going to add 20 minutes to your visit and you're not going to get reimbursed for it regardless. So, even if you schedule this child and say come tomorrow because I have this waiting room full of kids to see and I need another 20 minutes to do an assessment, you're not going to get paid for it. The insurance company won't pay for it because its preventive service or they decide they won't pay for it. So, that's another barrier. Some people...it's not the case in our situation, because we have Early Steps...but in some communities some people would not want to do it at all.

I understand. Another one that you indicated as a barrier is administering validated screening tools. Tell me what you're interpretation of that was and why it is a barrier.

What I meant is more for us to be able to do it ourselves rather than referring. I don't have the expertise to administer, other than the Vanderbilt and a few other ones, other sophisticated tools because its time consuming because we need to be trained. It's almost like me doing someone else's job. So, it's still a barrier because education...because it could be something general pediatricians should be able to do but if you're not in

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residency training, it's not a standard that all residents do it. So, if it's not required then you don't do it.

Now you could learn it on your own but that means you'd have to invest time to go to a course and invest time in your practice too...and are you going to get reimbursed? Some places may not reimburse you for administering a psychological test because you're not a psychologist. They only allow you certain codes so you can't bill for something even if you're trained to do it. So, I think if you can do some of the tests yourself, it might be faster and more convenient to the family because you could do it right there. You don't have to wait twelve weeks to get seen by someone. But training, reimbursement and time can be a problem.

Not every community has an Early Steps. Maybe in some communities, the pediatrician has to act as a psychologist, psychiatrist, this and that. But how much training they get in residency, when they get out I don't think they're ready to do sophisticated tests. They could do the common ones. They might interpret some tests that somebody has done, but they might not be able to administer them. And then, even if they know how or they train themselves how, they might not get the time or reimbursement to do it.

We have two more barriers to discuss. One is assigning office staff to assist with developmental surveillance. Tell me about why this is a barrier.

Some private practices, the screening questions we have from the Denver, they actually, to save time for the physician, the nurse or somebody in the office while they're checking the patient, they go through that list with the family when the child gets to the room. All

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the doctor has to say is “You failed three out of fifteen, lets talk about those only”. Or, the staff does it or the staff gives it as a questionnaire like what we do with the Ages and Stages...but more like give it to everybody and not just certain age groups...or these Denver questions. But they have to do it in an understandable language and then they fill it and then the staff can make sure it makes it to the chart. When the child gets to see the doctor, then the chart makes it to the doctor and the doctor scans it by looking.

It’s a barrier in our setting because, one, we have so many physicians and residents and parents already wait so long between the registration and they’re waiting to be checked in and the staff is busy doing too many things and to add one more thing for them to do is probably still a barrier for us. But for others I know, it’s do-able if you have a small practice with two nurses and three doctors or something. So you could probably train the nurse to ask those questions.

Ok. And the last barrier is financing the cost of standardized instruments. Let’s talk about the instruments you already use, since you spoke about the more in-depth instruments that you don’t use.

For example, the Conners’ ...we couldn’t use the Conners’ because we had to order them from the company and pay for them and whose going to pay for them? I mean, we might get reimbursed for the screening visit but they’re more expensive. We collect for Medicaid in a 10-15 minute visit anyway. So that’s why we ended up going with the Vanderbilt and we created our own sheets based on the Vanderbilt. So I guess we overcame it in some way and maybe some other ways like, I think the Ages and Stages

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questionnaires I think we order them, but I think initially [doctor] paid for the questionnaires from her grant for the study. But I can see it as a barrier especially if somebody doesn't know the Vanderbilt and they were only trained on the Conners' like we were and they're in a practice and paying for that might be costly. Now the sophisticated ones, I'm sure a lot of them are with a fee. So, I can see that, being other than the fact that people, even if they know, that's not what they do everyday, some reimbursement might not come to them because they're not the specialist.

It's like now, an example I'll give is we just started doing varnishes because the AAP wanted us to do oral health as a primary care physician. In North Carolina and some other states, maybe there are 30 states in the country, Medicaid actually reimburses physicians for a CPT code that's a "D" code for Dentist to apply varnish. Before Medicaid wouldn't do it and there's been some lobbying from the dental society to allow pediatricians to submit those codes and get reimbursed and Medicaid won't do it just because you're not the specialist. Even though the fluoride varnish application is like painting teeth, in some communities and schools, school nurses could do it. You don't even need a physician to do it. So, I could see even on the flip side even if somebody in an office who knows how to administer some of those sophisticated tests and is willing to pay for that if they can't get reimbursed, they might not do it just because they might not get reimbursed because it's a sophisticated test and you're not a licensed mental health professional to do it.

Ok. That is very informative. Are there any other barriers that you've thought of

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that I might have not talked about that you've noticed on a regular basis which interfere with your service to young children with developmental problems?

No, I think the big ones you hit on. I think training is a big thing and I really think in pediatrics, a lot of what pediatricians do is development. In the whole three years, there's only one month required for development so technically you're supposed to keep doing what you learn that month the rest of your three years. But I think that it's nice to have the community support. We have the luxury of an Early Steps but it has the drawback that we can be dependent on or we can refer so it makes me think are we over-referring things that maybe we should be able to take care of? Are we maybe not feeling the need to learn new things because somebody else could learn it and do it? So I'd say training is a big thing and time. A lot of those developmental issues take time and now we do like an ADHD visit...just to be ADHD. You can discuss it as part of any other visit and now its like when you see ADHD, it needs a visit by itself and I think time is a factor.

Ok. That is the end of the interview. I really appreciate your time.

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Participant Number: 2

Interview Date: 3/22/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset.

We can now begin with the first question. Ok. I'm going to be referring to the online survey that you filled out throughout this interview. The first question that I want to ask you is...you indicated on the online survey that you've been able to keep up-to-date about developmental issues, risk factors, screening techniques, community resources, etc. If we could go one by one, how have you been able to keep up-to-date with child development issues?

Usually through reading Pediatrics or the developmental people will send us little brief summaries of what's going on with either the AAP recommendations or...that's mostly it.

Who are the developmental people?

Primarily, [doctor] is one of the developmental pediatricians at USF and All Children's, so she's been working with us mostly. So, she'll frequently send us stuff.

What kinds of material does she send?

Usually it's just email or summaries of the latest AAP recommendations.

How do you receive information regarding risk factors, screening techniques, community resources, etc.?

For the community resources, usually we find out more of those on our own. So we send them to either Child Find or through our case manager we'll send them for developmental

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screening. That's mainly how we find out about those. The risk factors... usually through the AAP as well...and I forgot what the other one was...

The other one was screening techniques.

Same thing. Usually through the AAP.

And when you say through the AAP, what do you mean?

The American Association of Pediatrics...sometimes they'll have articles through Pediatrics.

And as far as community resources, are you saying that Child Find is the place that will tell you about resources?

Usually they do or Early Steps. We usually send our kids there and then they can help us direct the kids to the resources. They're two different things because Early Steps is up to three and Child Find is school-aged kids.

Another question you indicated was that you've acquired the skills needed to administer and interpret valid and reliable developmental screeners. First, what kind of developmental screeners do you use?

The primary one we use, well, we've taken the Denver which we've been trained on and we've abstracted some of the major questions from it and that's what we have on our normal well child visit checks that we show residents...so we've learned how to use the Denver...and the Ages and Stages questionnaire. Those are the two main ones we use for screening.

How have you and your staff acquired the skills for administering and interpreting

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these two particular screeners?

The Denver, I was taught in residency how to do it. The ASQ was actually, [doctor] taught us how to use it...and lectures also.

So you said [doctor] taught you. How did that come about?

She was actually doing a research study bringing the ASQ into different clinics to see if we could improve the amount of screening being done by the residents. So, she taught the residents and us through lectures, how to administer the ASQ and how to score it. It's pretty self explanatory. Basically you can hand it to the parent. It's about five pages of can your child do this, this, or this. You check it off, you write the score in and then you put a little circle into the box and if they are in the white part, they're good. If they're in the black part, they get referred. It's pretty self-explanatory. A lot of our daycares have used it. Like a daycare will send us an Ages and Stages that they've done on our kids and I know they're not developmental pediatricians either. It's pretty straightforward.

For all users?

"Yes."

How have you increased the time needed to administer and interpret these screeners at your site?

I don't think we've increased the time, but by handing it to the parents, they usually fill it out before they get to the room while they are waiting for the doctor. So, that gives us...at least these things are done and then scoring for ASQ is pretty quick.

So you give the ASQ to the parent?

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Yes, the staff up front, when they first check in, if they're at different ages they will have the Ages and Stages Questionnaire and hand it to them and say please fill this out while you're waiting for the doctor.

And the interpretation happens when?

Usually if the resident sees it, they'll give it to us and we'll go over it before we go back into the room for me to supervise them or while I'm supervising them, I'll notice it, grab it and go through it very quickly because it's very quick to score.

And the Denver, is that more for developmental surveillance during well child checks?

Yes. As I said, we've just abstracted these right onto the well-child visits so there's probably 60 questions that the residents ask the parents as part of the well child checks.

If there's a form, would I be able to have a copy of it?

Well, they're at different ages. Do you need one of each or just a sample?

Just a sample of whatever you can give.

That's not a problem.

I appreciate that. Ok, you indicated on the survey that you've been able to develop a strategy for providing periodic screening in the context of office-based primary care. We just touched on that a little bit so I will move on to the next question.

Another one is that you indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention/early childhood programs within the community. Can you explain to me the process that you use, from the

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moment the child is in your office to, eventually going to a program? What are the constants that are involved in that process?

The main thing that we do is that we run an order for our case manager to send the child either to Early Steps or Child Find or FDLRS depending on how old they are. Or, if we think it looks to be just a communication problem, we'll refer them directly to a speech therapist and an audiologist. Or, if it looks like problem solving, we'll send them to an occupational or physical therapist. So we write an order for our case manager, who then based on their insurance, sends them to the appropriate location.

So is the case manager the person used to help?

Correct. She identifies the resources for us that their insurance pays for and if it looks more global, we'll send them to Early Steps.

Do you ever make any suggestions to patients about certain community resources, and if so, how do you have that knowledge? For example, what if you're not referring to Early Steps?

Well I am a little biased in that my child had some developmental delays and he had been taken care of at Achieve Tampa Bay and there's also Easter Seals next door, and UCP near Tampa General. So it's some of the three local ones that I'm pretty well aware of their resources and two of them are local to here. So I figure if families can get here, they can probably get down the street."

So does the case manager help with that?

Exactly.

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Exactly what does the case manager do or what is their training? Are there any special degrees that they need to have?

I don't know the answer to that.

Ok. I was wondering if he or she was a social worker or...

She's not a social worker. She's like a well-trained office assistant but better trained than that. So, she'll take extra classes so she can manage other people doing it as well. It's mostly on the job training. We do have a social worker but she'll do more if there's a mental health issue or housing or transportation or something much bigger than that. The more routine developmental screening stuff she doesn't usually get involved with.

So typically the social worker is not involved in these processes.

Not usually unless there is an additional component like a mental health issue that we've tried going to mental health and we're not getting anywhere, then she may get involved.

Some of the kids may have comorbidity. It's like they'll have bipolar and developmental...even with ADHD we see so much of it and we're pretty good at getting the resources for them. But sometimes if they're still having difficulties then she'll get involved.

I see. You also indicated that you're able to determine the cause of delays or consult with the appropriate healthcare professional or another professional, whoever they may be, for determination. In general, what do you do to determine the cause of delays and then how do you know if you need to consult with someone else?

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Some of them are relatively straightforward and others, if they're premature, they're at a much higher risk for developmental delay. If they have a chromosomal abnormality, like Downs Syndrome or another more obvious where you can look at them and go "Oh yeah, they've got X chromosomal problem, etc." then it makes it pretty easy to determine their cause. If they don't have an obvious cause, sometimes we do some bloodwork looking for a chromosome abnormality. We may send them to genetics to look for a chromosomal problem.

If there's no cause and they look like a healthy, normal child but you can tell there's a developmental delay anyway, then we may send them to a developmental pediatrician like [doctor] to try and figure out better what's causing their delays. Sometimes we don't know a true source...there's no cause that we know. But they're still delayed so they still need services either way.

How do you go about consulting with other people?

Usually we've got an order for developmental clinic or Child Find or Early Steps, or something like that. The only other way we'll sometimes do it is if they're a little bit older, we'll write an order for the school to do testing. But, I'm sure for the people who do that, there's tons of kids and it takes a long time and the squeaky parent gets the testing first. So, there's a lot of our kids who just kind of fall through the cracks because the parents are unable to do it for whatever reason. The school is too overwhelmed so it's six months or later.

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Have you ever received any calls from anyone in the school system – any staff member – on the behalf of children or vice versa?

Pretty rarely in either direction. Once in a while but it's pretty rare.

Who are those professionals that you've had contact with?

The teachers we get a little more communication with because of the Conners' scales for ADHD. So, sometimes we'll get letters from teachers. That's not that uncommon.

Maybe once or twice a month we'll get a letter or note from the teacher saying "Help".

That's probably the main people that we get in touch with...and I'm trying to think if I've ever heard from a school psychologist...that's rare. Probably not. Maybe a social worker once, but again that's really rare.

Ok. You indicated that you've been able to maintain relationships with community-based resources and coordinate care with them through the medical home. Again, it kind of touches on what we were talking about before – basically you have that case manager that helps connect people with resource.

Being on the Board of Directors for [organization], I know the people there. Sometimes I've called them as well and found kids that we need help with and see if we can get them in sooner or see what else we can do for them. Those are the primary mechanisms that I use.

The next one that you indicated is that you've been able to increase parents' awareness of developmental disabilities and resources for intervention. How have you been able to do that?

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I think the ASQ has helped a lot of our families because they go through and say, “Oh, my kid should be able to do this or that” and they may not have realized it before when we asked them the developmental questions, just as part of the screening. They say, “Oh, I didn’t know my kid should be able to do that or he’s already doing that.”

How does that conversation proceed?

Depends...sometimes it’ll turn into “Oh no...he can’t do any of those things” and they didn’t realize that he was supposed to be able to do it. So we’ll say he’s delayed and try to get him some resources like therapy to try and help with that. Other times they’ll say “Oh no he’s perfectly fine, leave him alone, I don’t want any therapy, he’s fine.” And sometimes it will take several visits of “He’s still behind” to say “Yes, this is a problem and I am willing to address it”. Other times it’ll be that the parent will say that they’re behind but we as general pediatricians don’t see it ourselves so we’ll have them screened. Or, they don’t tell us anything about it but then they go to get them screened on their own. Then I’ll get a therapy letter saying that the kid is getting services when none of this came up at our exam and I just saw him a month ago. So sometimes I don’t even know where these meetings are coming from. But the daycare’s initiating them or the parent claims we said something during the office visit that we may not have noted. Sometimes I’m never sure where that happens but as much as possible we try to work with the families and say, “Yes, they do seem to be delayed or they’re premature” or “They do seem at risk for delay so even though they’re doing great now, let’s send them for a screening so they’re hooked up in case, as they get older, some things show up that

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weren't showing up now."

Are there any other ways that you inform them about developmental delays and what they need to do to help them?

The other, not as direct as screening, we're involved with the Reach Out and Read program here so we give children six months to five years old developmentally appropriate books and we encourage parents to read with the child. As we're doing that we say this will help the child read better. Early literacy increases their chance of doing well at school. So, we bring up that component of it as well, a little bit less directly.

Ok. Another one that you indicated is that you've been able to assist families with interpreting reports and feedback from other practitioners or other professionals.

How does this happen?

Every so often the family will bring in a report from the psychologist or therapist and they'll say "Here." So, we'll go through it and say they seem to be finding this and what they really want is for your child to get therapy or to see an ENT doctor or whatever it is to help the child.

One item that you did not indicate was that you present screening results to families using a culturally sensitive and family centered approach. What was your thinking behind not indicating this?

I wasn't quite sure what you meant to be honest.

I can provide an example for you.

That would be helpful. The patient population here is very mixed. We have 50% African

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American, 30% Latino, and 10% White so we have the gamut of some well educated and mostly not well educated. So, I feel like I'm working with that group anyway but I don't feel like I tailor it for each population except for translation services maybe...

Ok, here are a couple examples. What if you run into a family whose native language is not English or what if you run into a family who has been poorly educated and has difficulty understanding certain concepts? How do you help them understand? How do you help that family that doesn't speak English?

We do have a lot of bilingual families and we have Spanish-speaking staff who translate for us. We have a Creole-speaking person but the other languages we have more trouble with. So if they're bilingual and we're not sure, that usually comes up more with the communication issues. They're going to be bilingual later and therefore they're delayed and there's some controversy about that so we try to get them to a bilingual speech therapist or someone who can assess at least in their native language are they ok or not. For the less educated, we try to explain it in as basic language as we can. Sometimes we've tried multiple times and we just can't get through. Sometimes I sort of force the issue and say, "Why don't we just send them to the therapist because I may be wrong". They may be perfectly fine and maybe they can test them more and as the parents watch the testing then they may say "Oh, they're not doing what I thought they could do." Sometimes it gets to that level and sometimes I can't get anywhere and the family just refuses and I can't make them test a child at this age unless I call DCF which is what I don't like to do. So, usually I tell the family next time if they're still delayed that he still

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hasn't done these things that we wanted him to do, "Can we get him tested please."

So, are you saying that you try to break the information down, verbally, as much as possible?

Right and during our exam if the child's not doing it we'll show them what we want the child to do. We'll be like, "Oh look, he should be sitting". We try to sit him and he'll flop over and we then say, "He's old enough, he should be able to do this...we need to have him tested to make sure he knows how to do what he's supposed to do." Or, "He's two and he's still not speaking and other two year olds are doing this. I can't understand anything he says and you can't either". So, sometimes it involves showing them what their child is not doing.

How about if there's a parent who can't read? Does that ever interfere?

Probably, we don't really ask about literacy skills of our parents as much as we should, so that is probably some of the cause.

The last section that I wanted to talk about with you is the list of barriers. I will first talk to you about the ones that you felt were not barriers and have you explain to me why they are not barriers...administering validated screening tools...this is not a barrier for you why?

Because we have part of the Denver on all well-child visits and we give the ASQ to families at certain visits. So, hopefully we've addressed getting it done. Residents also assist with asking questions at well-child visits.

Scoring the validated screening tools? Why is this not a barrier?

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The ASQ is pretty easy to do and the Denver we extrapolated, just the small portions.

We get our answers pretty quickly.

Referring families to community resources, why is this not a barrier?

We have a case manager who is able to get a lot of the resources taken care of for our families, but it's not perfect. Some fall through the cracks. We send them letters and they don't get them. They changed their phone number and didn't tell us. So it's kind of a mixed barrier but we tend to address it as best as we can.

Assigning office staff to assist with developmental surveillance...we talked about that a bit already and why that's not a barrier. And financing the cost of standardized instruments like the ASQ, which is pretty much the only one you use...

[Doctor] has a grant that she's doing and she will bring us ASQ's. It's not a very expensive test to do.

The one that you left off was attaining reimbursement for preventive service. Why is or why does this continue to be a barrier?

Insurance companies will sometimes limit the number of tests or they'll limit the number of providers that we can refer our kids to and if they're too far away for our families and they can't get there, they may only pay for ten speech therapy visits and the kid needs a lot more than that and we can't get paid for. So, then we're trying to either send them to some other community resource to try to hopefully get it paid for or get it for free or get it done through the school where it doesn't cost anything, but getting the testing can be

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quite a barrier.

How successful are you guys when you run into these barriers posed by the insurance companies and you've had to find other methods

Thankfully for the little ones, Early Steps is available and the older kids there have Child Find or FDLRS. So we usually get them started somewhere but in the school system they often don't have enough therapists for the kids so we have kids supposed to be getting speech therapy two times per week who only get it once per week or maybe not at all because there isn't anybody. We're not as successful as we'd like to be. We know that there are kids who are not getting the services that they need.

Are there any other barriers that we have not discussed...barriers that you run into on a regular basis which disrupt the whole process of screening, identification, and referring kids?

Referring really is a pain because a lot of our families are from low socio-economic status and sometimes they'll make up addresses, phone numbers, or their cell phone will be good for an hour after their visit - then its gone. So, you're trying to contact them again and send them to the speech therapist or here's your appointment for this and they never get the letter. They don't understand it, they ignore it, or transportation is broken down so they can't get to the appointment They have two other kids that had issues at the same time so that kid fell to the wayside. So, that's the most frustrating part. Not only referring, but getting them to the actual place on a consistent basis. It's often very difficult for our families.

I have one kid, its been six months now that we had referred him to the speech therapist

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and audiologist four different times and the mother said she's never gotten letters, never gotten phone calls, we refer again and the same thing again. This kid is behind. He's been behind six months! I don't know what else I can do except try to get the case manager and her hooked up at the same time. Hopefully they have the same number for 45 minutes. Unfortunately, this issue is very real and that's probably the most frustrating thing."

Thank you for your time. This interview has been very informative.

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Participant Number: 3

Interview Date: 3/29/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset.

You indicated on the online survey that you've been able to keep up-to-date about developmental issues, risk factors, screening techniques, and community resources.

First, let's talk about child development issues. Tell me how you've been able to keep up-to-date and increase your knowledge in this area.

Well, I read a lot. I read the PREP which is a Pediatric Educational Program from the AAP. PREP stands for Pediatrics in Review. Also, grand rounds at All Children's and, I'm personal friends with a couple specialists in town and I do consult with them a lot.

How about child risk factors? Are there any additional ways you stay up-to-date?

Well, child risk factors...I am a mother of three boys, so my personal experience is one. I not only read medical magazines, but sometimes you learn even more from the lay press than in medical magazines because some medical people are in "Mecca" and they are totally disconnected from reality. I have...I did not go to private practice straight from residency. I worked for the Public Health for four years in Liberty City which is a very poor African American area of Miami where most of the 1980s riots occurred. So, I worked there for four years in that community so I learned a lot there. After that, I became an assistant professor of Pediatrics in Loma Linda University in California. Part of my job there, not only was teaching and doing private practice, but also I was part of

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the Child Protective Team, a team that specializes in diagnosing child abuse – I was specifically involved in the sexual abuse aspect. During those years, I had to read about the risk factors and the peaks when children get abused the most. I had to testify in court all the time. So, I needed to know those. Then I moved here and I decided just to go to private practice because that job was too stressful.

So, would you say that your experience is atypical, considering you've worked in those different environments?

Yes, very atypical from the regular pediatrician who just went straight from residency into private practice like this. It's just completely different. This is a practice that covers middle class to high middle class and very educated people. Sometimes they read more than you do. They're up-to-date on everything. The other population I used to deal with was very poor, uneducated, immigrants...I speak Spanish so I was working with the Spanish community a lot. They have a lot of very strange ways of approaching health issues.

Can you elaborate on that?

Well, depending on cultures, for example in the Mexicans communities, you may see a child with some dark lines here [pointing to the abdominal area)] and what they do is they pass a coin because they believe that will keep evil spirits away. Somebody may confuse that with abuse and it's not abuse. It's just things they do. The Haitians have voodoo and you had to make sure they are not giving one of their mixtures to their children. So, right now I'm in a practice where most people have the same background as

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I have and they treat their kid the same way I treat my kids. So, it's easier... and in those other communities, you had to keep up with the culture that you were dealing with and with the new wave of immigrant that was coming because that was my job and I needed to know what they were doing.

So in keeping up with these cultural differences, you were...

It was just by talking to people and saying, "Why do you do that". For example, we have a lot of Indians from India and I ask them why they put the cord around the baby's belly and why do they put the dot on their forehead and what does this mean and things like that. I just ask because I want to know why they do that.

So, it sounds like you're taking an interest in them.

Yeah, I want to know why they do that.

Ok. Another component involved your keeping up with screening techniques.

Yes, let me show you what I use. This is Pediatric News, a newspaper published by the American Academy of Pediatrics that keeps me updated with pediatric news. Sometimes I read articles that are very helpful and I save them. For example, this article from last year discussed how to screen specifically for Autism and depression and directed us to a web site (brightfuture.org) which these forms could be downloaded for free and used in the practice. I immediately implemented those forms and started using day to day. I downloaded the M-CHAT (a screening tool for the detection of early autism), BECK (a screening tool for depression) and this PEDIATRIC INTAKE FORM that I found

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extremely helpful during my initial intake of a patient with behavioral or academic problems.

When did you start using these?

I read about this about a month or two ago. I don't use it on every single patient but I use it on some patients for which I am concerned. You know when you have been a pediatrician for a long time...(I've been a pediatrician for almost twenty two years) you immediately perceive that there's something wrong with this child ". Then you have to confirm your suspicions. I screen the patients by using these forms. Also, everybody with behavioral problems in this office, usually makes the appointment with me. I also use the Vanderbilt ADHD questionnaire to screen for ADHD. It does have very simple questions that not only screen for possible ADHD, but it also screens for anxiety and oppositional defiant syndrome...It's a scale and very easy to score.

[Looking at both protocols] Is it both English and Spanish?

Yes, but we don't use the Spanish version because this is mostly an Anglo practice. The part that's in Spanish is for resources. Sometimes you give this to parents to explain what needs to be done involving the teacher and at home. The AAP developed this so pediatricians could get a little better with the mental health situation that we have. It's very difficult to send a kid to do a screen. Insurance doesn't pay for it and parents don't like to pay for it...and then you're stuck. What do you do with this child who is not performing in school or he's not talking? By using these tools, you can say, "Ok. I have a problem" and then you have a better indication of what to do.

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The parents usually come and say their child is not doing well in school. They make an appointment to discuss the academic underachievement. Then I hear what they have to say and sometimes it's not ADHD. I have a questionnaire I developed that screens for environment problems. I specifically want to know if the child goes to sleep on time, if the child has a structured environment, who lives in the house, if there's violence in the house or are we dealing with a developmental issue that is impeding this child's performance. Then I skim through it. I'm looking for a medical reason that would impair the child from performing.

Once I determine there is not an obvious medical or environmental reason for the child's difficulties I hand out the Vanderbilt Questionnaires. You give a questionnaire to the parent and I tell parents to give the teachers a stamped envelope addressed to me so the teacher can be open about what's going on with the child. Then I score them. I am not a behavioral pediatrician or a psychiatrist. I do not prescribe antidepressants or anti-anxiety medication. But, I do prescribe for ADHD. I don't have the ability to do psychotherapy. I'm not a psychologist so I don't want to get into that. I do screen for these mental issues and direct the parents to the appropriate specialist. Sometimes I may find that the child is very depressed and they do not have ADHD. Depression is what needs to be treated so that the child performs in school. The other day during an Academic Underperformance evaluation I administered the BECK screen for depression. A score of six indicated a child may be depressed. My patient scored twelve. So, I informed the parents right away that their child is very depressed. I stressed the fact that

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this is not a transient, teenage thing and that the child needed immediate psychological and psychiatric evaluation. Had I not used this form, the child would not have gotten the help he so desperately needed.

Many patients are underperforming due to substance abuse. If I am evaluating a child with new onset of symptoms (ie: academic difficulties) and the child has been diagnosed as ADHD by a Psychologist, I tell them I will not treat them unless they give me a drug screen that's negative. I'm not going to give more pills for them to sell out there. So, if they want to get treated by me, they need a negative drug screen...and I'm not going to do it. I'll tell their parents to do it on a Monday or Tuesday afternoon or after a vacation. I do have certain rules on how to proceed with ADHD therapy in this group of patient.

How about the parents of younger children? Are you seeing similar concerns with ADHD?

Well, younger children don't go to school. So, they're not having any problems with performance. I'm very big on discipline and not everybody agrees with me. So when I get a new baby, I tell the parent that, to avoid problems...because I'm big in preventing...I give them this big speech on how to, from day one, start structuring the house. The baby's life needs to be structured. The baby needs to learn how to sleep. The baby needs to soothe himself. I talk to parents about the different developmental stages and how children learn behavior. The first five years is imprinting, the second five is mostly imitation, and then comes socialization. I am big on the imprinting part because they need to learn that "no" means "no" and "yes" means "yes". Don't make a promise

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you cannot keep and don't make a threat you cannot follow through with. Be consistent and don't fight every single battle. When you do decide to fight you need to win. I tell them they need to do that before the age of three because after this age, it becomes more difficult. I am very big on that so, with the early children I try prevention a lot. I tell them not to fight over eating habits and not to give the child too much power. Sometimes I give the speech and the parent decides that I'm not the type of pediatrician they like. They go to one of my partners and they come back in about four or five years with a rotten child and they want me to fix it and it's too late. But, I tell them this is what they can do. I follow many children from birth to young adulthood. My goal is to prevent them from getting in trouble and that the parent maintains an open channel of communication.

That sounds like there are stages of parent training that you go through.

Yes. I do a lot of parent training but that's because I like it.

And with those young children, earlier you talked about some screening measures that you use, but these [pointing] apply to the younger ones too right?

That's the autism one. And also the intake form that's for the environment. If I do the intake and I realize the mother had been abused or her boyfriend abuses her, of course this child is not going to do well in school. We have to fix the environment. I can't tell mom to kick the boyfriend out, but I can direct mother to organizations that may help her such as CASAS. Treating a child for ADHD without addressing the abuse problem will not help at all.

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What are the methods you use for developmental surveillance?

Well, we have...I have to get a computer to show you. I do it this way because it's easy for me to score it. I can score it just by looking at it. These are the Vanderbilt Questionnaire. These questions screen for Oppositional Defiant...these are for anxiety...and this is the teacher's. There's a similar one for the parents and we also have a follow-up we use to monitor progress.

Now for surveillance, we have a computerized system of charts and I'm going to open my son's so I don't break HIPPA laws. If I'm doing a physical exam and my son is a toddler, I would put "male-infant". Appropriate developmental questions will pop out in the screen and then I choose, let's say, "12 month old" child. This child should be pulling to stand, be sitting up, standing for a couple of seconds, starting to combine...So, I start asking if their child is doing this. If they say no, she or he doesn't, then I may say we have a problem and I would do a more thorough evaluation.

So...if the child is eighteen months I will ask if he can walk backwards and can he run. He should say at least three words. Actually, this is a little bit too nice because by eighteen months they should be saying more than three words. But, the minimum should be three words. Then I always have a pen to see if the child scribbles or eats it. Like at five years, before entering school, you know, I tell them I'm going to play games with them or we jump and we write and I make them make a drawing of themselves because that brings a lot of information on how they hold the pen. They think that they're playing games and having fun but I'm doing a thorough developmental evaluation...If the child

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refuses to play the games or if they do not hold the pen appropriately that may indicate red flags and I may refer them for further testing. I have sent a couple of kids to occupational therapy that would have fallen through the cracks had we not played the “drawing games”. So EMR helps a lot.

How did using this computer come about?

Because that’s where the medical records are going. Electronically, we don’t use chart records. So, tomorrow I have those [pointing] patients and when they come, I will see all their information.

Regarding the form that you gave me, when and where are the parents filling them out? Here? At home?

The teacher and parent evaluate for the Vanderbilt...they have to do it at home. The autism, depression, and family intake we do here. I keep them busy. Instead of waiting in a room, they’re given some paperwork and they feel that they haven’t waited that long. By the time they’re done with that, I come in. Sometimes I send their child out...the reality is that you have to see X amount of patients an hour or else you don’t make a living. So, I had to find some creative ways of being able to give them a little bit more time while still seeing patients. Sometimes I do use the forms for them to fill out. I see a couple more patients for ear ache, sore throat, go back and read it...ok, now I need this...so the flow keeps going and I’m still going back and forth to that room.

Another item involved you keeping updated about community resources. How are you able to do this?

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That one is a little bit harder. Usually, I learn about community programs through the mail.

The actual community resources?

Yes. The resources [looking around], I don't know if I have anything here. I receive a lot of cards that we are...we have compiled a list of psychologists and mental health counselors that we like or that accept insurance. We had a nurse here whose child had severe psychiatric problems and she took special interest in finding out resources that were available and that was her cup of tea...to do all this stuff. So we have that.

I would say that's my weakest point. It's very hard to keep up with the community resources but unfortunately there are not too many good community resources to unless you have money. That's the reality of life. Unless you have money, the resources are terrible. Mostly, I learn from experience or from my friends. I have friends whose kids have been in a lot of trouble and they send them to special programs. These parents inform back whether that program worked or whether this one was not good. Learning about programs that way works well. Sometimes the brochure tells you that all the services are available, but in reality it does not work like that. However if there's a weakness, especially for me, it is that I am not aware of all the community resources we have out there. I'm just aware in general and if it's an academic issue, I'll have to direct them to go to school and ask them what is available. One of the reasons I like to screen for autism is because I know there are a lot of programs for autistic children that can help. I've seen major improvement of children who are autistic or borderline autistic if you ge

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them early and you intervene early, especially with their speech.

And you said you refer to the school...have you ever worked with anyone in the school? We talked about the teachers a little.

Well, they send me those forms and if they write down...and sometimes it's a big "if I have time"...if they write down "please feel free to contact", sometimes I do. That's especially if the child's not doing well. But, we do not have the time or the resources. I don't have anybody I can pay to call and see how they are doing in school...and I cannot charge for services like that. So I am limited financially. Now if they call me, I always return their call.

Does anyone from the school reach out to you?

Sometimes.

Who?

School psychologists. There was a particularly good school psychologist who used to call me to tell me that a medication was not working or that the child was having other problems. She was very good. She left that school and I haven't heard from the new one. In my fourteen years in practice, maybe two or three guidance counselors and school psychologists have reached out to me, but very few.

Overall, was the outcome beneficial?

Yes. Extremely beneficial because then I know the reality. It's one thing when the parents tell you and another thing when you know what's really going on. Sometimes

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you have to take everything with a grain of salt because I had a specific child, probably super ADD, who was in an Emotionally Handicapped class and everybody there is so bad and the teacher writes him down like he's an angel...and he's not, I can see he's active. I'm thinking that the teacher is overwhelmed with horrible cases there, so he's not that bad. So, she marks it in comparison to the others. If a teacher is sending me an envelope, from an EH program, I know what may be happening. It's important to live in the community that you serve, and it's important to know the schools. Private school teachers tend to be more open about communicating with you than public schools. The classes are smaller, usually the teachers know the parent, they live in the same community...it's a community school. So there's more involvement or more interest in that child because the child may be the teacher's neighbor or the teacher's son's best friend. The public school teachers could care less [laughing]. We have a lot of patients who are teachers and they're wonderful, but they're overwhelmed. They can't...and besides, I think what makes a school better is the community. If you live in the community you teach or you practice in, you know the people, you know where they live, what school they go to, their family, and you know their problems. You know this child is acting out and you know the husband is a little bit violent and it's very hard to know that if you don't live in the community.

I'm sure you're studying this, but why do Catholic schools with such terrible budgets and they don't even have teachers that are accredited, why is it that they do such a good job? Because they are a community school and the teachers there live in the same community

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and the teachers...they're your neighbors. My kids went to Catholic school and if one of them got out of line, I was getting a phone call. It's your community and you don't want to see the kids in your community go astray.

I understand. You also indicated that you've been able to present screening results to families using a culturally sensitive and family centered approach. Talk a little about how you've been able to do that. Give me an example.

I try to be sensitive with anybody. Well, I'm Spanish so if it's a Spanish family, I'm speaking Spanish. I try to learn the background of my patients as much as I can...where they are from, etc. We have a lot of Bosnians. They come here and they are Muslim. For example, if their belief is that the girls are inferior, I will not go for that. I will try to present it in a sensitive way, but I do not know how to answer that question.

If you had a parent who has limited education, how would you go about explaining the results to him or her?

I have a father with a very low IQ and he's really trying hard. I talk to him and I let him know that this person is taking advantage of him and that he should do this, but there's not much you can do. But yes, I try to go to their level. I never explain things in medical terms. I explain things with comparisons. For example, when I'm explaining an immune disease, which is a difficult concept to understand, I tell them that you have an army and the army is your immune system and we have different branches such as the army and navy. I explain how each system works and the job of each cell. An example I use the most when I'm trying to explain to a child that he has ADD, I ask them if they play

Appendix G (Continued)

sports. They usually say “Yes”, and then they say something like soccer. Then I ask what would happen if they showed up to a game and their coach didn’t show up? No parents...just the kids. Then he would say that they wouldn’t know what to do. Then I say, “Who do you think is your body’s coach?” and he’ll say “My brain”. Then I say that when he wakes up he is like a soccer team without a coach. Everybody’s there...all the components are there but there’s no one telling them what to do. So, I say that sometimes we have to wake up the brain so that in the morning when we wake up and go to class, the brain is not sleep. Then you can pay attention.

The next one I wanted to talk about was...you indicated that you’re able to refer kids with developmental issues in a timely fashion. What are the steps that you take when you know something is going on and you have to refer?

As I said, I use all the screening techniques and I use my questionnaires and before you leave I’ll give you one. When I use those questions and I feel it’s something I cannot handle, I give them my list. Say I have a doctor or psychologist here who takes most insurance and he’s pretty good. I can send a lot of patients to him and he can screen them and I know about FDLRS for children with Speech impairments and I refer them there. I refer a lot of kids for physical therapy for fine motor concerns.

Another question that you indicated is that you are able to determine the cause of delays or consult with the appropriate healthcare professional. You told me that you do screenings to determine this. So how do you determine whether you need to consult with a healthcare professional or someone else.

Appendix G (Continued)

Oh, I know my limits. I know that if I have a child with an antisocial personality, I can't handle that...or a child that's depressed. Or, if I try to treat someone with ADD and it doesn't work...manic depression, bipolar disorders, the ones that just blow a fuse...I cannot do it. You have to go a psychiatrist.

Ok. You also indicated that you've been able to increase parent awareness of developmental disabilities and resources. We talked about the resources you referred them to, and again, how are you able to keep them informed...up-to-date on what their child needs?

Most parents here know more than we do because they know their child has problems and they have gone to the internet and learned everything there is to know about that.

Then you have the parents that you have to tell them to go to the school because they are entitled to this and that. One of our patients is a school board person and she is fantastic and I call her too. I tell her I have a kid with this problem and ask what I can do. And she tells me to tell them to give her a call or write me or fax me and I'll look at the case.

And how about if a family comes in and gives you a report from someone else? Do you generally find yourself able to interpret those reports?

Yes.

Ok. We're at the barrier section and we've gone over a lot of these. I'm going to read through the barriers and I want you to tell me why it is or is not still a barrier for you.

You indicated that obtaining reimbursement for preventive services is a barrier.

Appendix G (Continued)

Tell me why.

Because they don't pay for the amount of time. Some kids need an hour but they're not going to pay for it. I cannot charge for an hour worth of mental health. Mental health is something that the insurance company won't pay for period.

Do you know why?

That's insurance. That's the law I guess.

Here are a few others that you mentioned as barriers, although through our conversation it's sounding like you have overcome them. They are administering and scoring valid screening tools, assigning office staff to assist with developmental surveillance, and financing the cost of standardized instruments. You've been very resourceful in finding and using screening tools online, etc. You've also figured out ways to incorporate the completion of these tools at home or while the parents are waiting. Therefore, you can assess children and you are not worried about the costs associated with administering tests. Oh, and you also have the computer which assists with gathering developmental information. The only other existing barrier would be assigning office staff to assist with developmental surveillance. Why is this?

Not enough staff or time for additional things.

Ok...and referring families to community resources was not considered a barrier because of the assistance you've received from a nurse who has worked on finding resources.

Appendix G (Continued)

Right.

Ok, this has been a wonderful interview and I thank you for your time today.

Appendix G (Continued)

Participant Number: 4

Interview Date: 4/6/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset.

On the online survey, you indicated that you're able to keep up-to-date about developmental issues, risk factors, screening techniques, and community resources.

The first is child development issues. How do you stay abreast with those concerns?

By articles, reading periodicals and journals, American Academy of Pediatrics, Pediatrics in Review, and other pediatric journals.

Are there any other methods you use?

We use going to meetings where lectures are given. Like next week I'm going to a seminar at Ft. Myers hospital...it's a two-day seminar...and they'll be various topics discussed there and we'll get continuing medical education. So I do the audio digest, journals, and seminars.

The other one was child risk factors – are there any additional ways that you keep up with those?

No, that's about the way I do it.

Screening techniques – how do you find information on that?

I don't use a lot of screening techniques. I have not been one that uses those. I have not found them very helpful.

Can you expound on that?

They're time consuming and I don't have a lot of time to do them, and when I'm through,

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I'm not sure what I've accomplished other than what I see when I examined the patient and talked to the mom. I used to use it when I first started. I really didn't find them that useful. I just went on clinical evaluation because they really didn't add much.

And how do you keep up with your knowledge about community resources?

We have several pediatricians in our group. We talk with each other and we have meetings. I'll say, "I've run into this problem...have you run into that yet?" and they'll say, "Yeah, I've found this source was good." Other pediatricians in the community and in our group are helpful with that. We have one pediatrician here who is very interested in developmental problems, attention deficit disorder, autism, and many of those types of conditions. He really enjoys and has made a special effort to become well educated and gain expertise in that area. If I have a question, I'll go over and talk to him and ask "What school does this" or I'll use Child Find a lot and I use the Early Development Program over there. But if I want something specific for a specific problem, I'll ask if they've found the psychologist that really hones in on that area and that's the way I keep up and find out about those special issues. Our nurse keeps a list of numbers for resources like Child Find and others.

Ok. You also indicated that you present screening results to families using a culturally-sensitive and family-centered approach. Please provide an example of how you've been able to communicate this information to families.

Well, I try to be sensitive to cultural backgrounds. Again, I don't use a lot of those Denver developmental things.

Appendix G (Continued)

For example, I don't know what kind of client base you have here, but say in the past you ran into a client who had limited English proficiency or limited education?

Those areas are difficult to deal with. You do the best you can to try to explain to them in terms that they're going to understand. If it's an English thing, I even have looked for somebody in the building that speaks Spanish and there is one of our nurses who is good at speaking Spanish.

The toughest one I ever had was a Japanese family who spoke almost no English. I couldn't get anybody to translate so I struggled and that family, fortunately, didn't have a developmental problem. It was just ear aches and sore throats. I don't know what I would have done if it was a developmental problem. For that family I would have had to go out into the community. Those folks did have a relationship with other Japanese people within the community and one time we were discussing a problem and the parents didn't understand and they gave me the name of a friend to call and talk to and I communicated through that 3rd party. It was just people that they knew in the community that they were close with and that's kind of the way I approach it...

For that particular situation, did it take you a while before contacting that 3rd party?"

Yes. He was working. But most of the time I can find someone to interpret for me.

Ok. Another question is that you indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention or early childhood program within the community. You just stated that you have

Appendix G (Continued)

resources that you refer children to. Can you explain the process you have in this particular practice?

Ok. There's a problem and if the child is under three, most of the time we send him to the early developmental program. That's a good resource for me. We start there. If they're over three, then we have to do it more because at USF they'll see the child and then refer to areas of other needs. Frequently, they'll need to see the Endocrinologist, Neurologist, and Geneticist. They have all of those there at USF so they can serve as the center and refer out and then I have to do that here over three and Child Find is a good place to start. They'll do hearing, vision, and developmental assessment and then if they're specific problems like neurological problems, I have various neurologists that I refer to. USF clinic does under three year old referrals. They're so good at doing it, unless that parent requests that I do it.

I understand. You also indicated that you're able to determine the cause of delays or consult with the appropriate healthcare professional. In general, what do you do to determine the cause of delays?

I send them to the neurologist because for many of the developmental problems, there is no etiology that we can put our finger on for many of them. After we do a routine workup, we don't find a reason. It's hard to put your finger on what the problem is. There's one family that has a child that I'm thinking of now that we've sent to numerous places all over the country and has a marked developmental delay. Nobody's been able

Appendix G (Continued)

to put a name on it and there's been an unknown etiology. He's seen world-class neurologists and geneticists and he's been treated at the USF program. Some of them you just can't find out.

When you're doing your routine workup, what does that entail?

Sometimes you do blood work, sometimes you do genetics, and check and make sure that they're growing and getting the proper nutrition. It's just a process of evaluating the patient.

How do you implement developmental surveillance?

Most of the time the moms are suspicious and if I see something I'll ask if they're concerned about something and they'll say, "Yeah, I'm glad you brought that up." I watch to make sure that there's truly a problem before I bring it up because I don't want to put something in mom's mind that shouldn't be there. But, most of the time they know and as you start to bring it up, they jump at the chance to talk about it. Then I'll say how about we go over to USF and get evaluated. They'll do some tests and some blood workup and depending on what they find, they may do more. Or, they may say that they haven't found any concerns.

Going back to consultation, we talked about different pediatricians and their areas of expertise within your group. While staying on the consultation topic, do you ever consult with other healthcare professionals directly or just refer your patients to them?

Yes I do. If I have a concern or if I'm having a problem getting a child in, I'll sometimes

Appendix G (Continued)

call her or one of his or her folks. Sometimes it's hard to get an appointment so if I call sometimes it helps.

In addition to that, are you able to consult with individuals within the school system or vice versa?

With the school system, it's more of them through the parents really. My contact with the school system is mostly with kids having ADHD, which I have decided that I don't do. It's a very complex problem and I have just gotten out of doing ADD. But when I was doing that, they were contacting me through the parents indirectly, trying to get the kid on medication. It could be the teacher or the school psychologist who thought the kid needed to be on medication. Frankly, feel that a lot of kids are labeled ADHD and put on medication when they shouldn't be on medication.

How do they present themselves to you?

Most of the kids are behavior problems in school so they want to calm them down so that they are not disrupting in school. That seems to be their goal. That's how it comes across. As long as a kid doesn't cause trouble in the classroom...that's our main goal. And the parents just want the problem to go away. Give the child a pill and make the problem go away and they don't want to do all the other things that are required. You know, you've got to make sure that the child gets their homework done every night. You've got to make sure that the child is taking his medication...parents...many of them just want the easy solution.

Is it a lack of education?

Appendix G (Continued)

I'm not sure if it's a lack of education. It's more like a lack of involvement. Really, they're not involved with their children as before. They go to daycare and they go to work, and both parents work, and mom's not home. I think that's a big problem. I'm sure ADHD didn't just develop...it's been there all along. But mom was home, you had family support and there was discipline. A lot of these attention deficit disorder children can be disruptive. But, if there was pretty strong discipline and structure...that's the way we've made it in the past I'm sure. Many probably didn't graduate from high school, they quit when they were 16, but they all seemed to make it. They all were citizens that were valuable to the community. But the family structure is no longer there. There's no discipline to go to school and if they are disruptive, there's not much the teacher can do but call the pediatrician to try to put him on a pill to control him. I was very displeased with that. I decided that I wasn't going to be a "refill Adderall" doctor. Luckily, when I did, we have a child psychiatrist that I refer my school behavior problems to. I don't abandon them, but I have found a place to go.

I understand...Ok, you also indicated that you've been able to increase parent awareness of developmental disabilities and resources for interventions. What are your methods for educating parents?

Just things that we talk about. Look for this problem...you're going to run into problems here and there. That's it generally.

Do parents call you to ask questions?

Appendix G (Continued)

Sure, I have one child that's a teenager and I've been taking care of him since he was two. He injured his spinal cord, had asthma, scoliosis, all the problems with being a paraplegic...a wheelchair...He's at the point now where he has a dog who helps him. The dog can open the door and turn out the lights. So, I've kind of grown up with him and he's been an education for me.

You also indicated that you've been able to assist families with interpreting reports from other practitioners...

I get that all the time. A little girl got an MRI and they told them it was abnormal. There were problems and mom called and asked me to interpret it for her. Frequently, when I've referred them to someone like a specialist and they found a problem, they come back to me for reassurance and interpretation. I interpret the findings in a reassuring way so they understand that there's a problem but we can fix it. They come back to me because I've been there all along. They trust me more than the high powered guy who obviously knows a lot more about the disease and treatment, but I get feedback from the specialist and then feed it to the parents. They hear the same thing from me that they heard from the specialist, but because I know the family and I've been with the family, it's different. I try to present it to them positively no matter how difficult the results are and talk them through the steps.

I understand. Another question noted that you have not been able to acquire the skills needed to administer and interpret valid and reliable developmental screeners, but we discussed that you don't find value in using the screeners...

I just don't use them so I'm not trying to keep up with them.

Appendix G (Continued)

Right...the other one was that you've not been able to provide a strategy for periodic screening in the context of office based primary care.

Well I thought you were talking about developmental tests. I do a screening every time a child comes in for developmental problems, check ups...stuff like that.

Do you use any protocols that you've created?

No.

Now I'm going to go through a list of barriers and have you tell me why they continue to exist as barriers for you. One barrier is obtaining reimbursement for preventive services.

Just funding in general is sometimes a problem...for folks who don't have insurance or who have inadequate insurance...just funding.

And for what different reasons is funding a barrier to preventive care?

More families can't afford insurance. They can't get Medicaid because they make too much money. So, those families are having a hard time just getting in for routine checkups and sometimes immunizations. Just basic things can be a problem.

The vaccine for children problem is a real help if a family has no insurance. I can use Vaccine for Children to get vaccines. They don't like to go to the health department because there's a stigma associated with going to the health department. But just to come in for a checkup is expensive, especially if you don't have insurance.

The insurance companies will pay a percentage for a certain level of care. The doctors and clinics all over the country keep raising the price and the insurance companies pay a

Appendix G (Continued)

percentage so they have to keep raising the price of the service so that they can make a living and pay their health. But, that drives the office visit price for the people who don't have insurance so high until they can't afford it. If you don't have insurance, there's no way I can say that I won't charge them the same price as those who do have insurance. The price of getting medical care has gone out of sight. The cost of a day in the hospital can be three, four, five grand. There's nobody who can afford that.

I see...ok...our last barrier is assigning office staff to assist with developmental surveillance. I realize that this is not a barrier for you because you do it yourself.

Correct. I do my own.

Financing the costs of standardized instruments is not an issue because you stated that you have your own methods of doing this without using instruments. Is there any other information that you'd like to add at this time?"

No, that's about it.

Ok, great. Thank you so much for your time.

Appendix G (Continued)

Participant Number: 5

Interview Date: 4/17/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset

How many hours per week do you see children?

Thirty-two...at least.

The first question you indicated on the online survey is that you've been able to keep up-to-date on developmental issues, risk factors, community resources, etc. How do you keep up-to-date about things in your career?

Usually, I use Pediatrics in Review which is a journal that I get once a month. I'll not read it in depth, but I'll thumb through to see what catches my interest.

Is it typically journals or are there any other methods that you gain information?

That's the biggest. I get some AAP emails from time to time that send me to links on the AAP site.

Is that free?

You have to pay for that.

And would that include information on risk factors, screening techniques, child development issues...all that stuff? Is that how you stay updated...through journals and emails.

Yes.

Ok, and how about community resources? How do you stay up-to-date on those?

I don't know if I stay as up-to-date as I indicated on the survey. I get the brochures that

Appendix G (Continued)

they send from EIP...HOT DOCs is one of them.

Another one that you indicated was that you refer children with delays in a timely fashion to the appropriate early intervention. Can you tell me how that comes about? What procedures do you use before getting to referral?

Well, we assess them at every well-child check and we just have a few questions, four or five, within the developmental area...the social, fine motor, gross motor, language, and there's just a few screening questions that we do. Also, I ask if there are any parental concerns as well. If there are a couple areas that look like there are some issues on the developmental screen as part of the well-child check, or if there are some parental concerns that I see, I usually refer pretty immediately because I think it's a little difficult for my patients to get in because there's so many patients and not so many doctors in this area.

To get into...?

EIP for a full assessment.

Is that one of your main referral sources?

Yes. That's it for the zero to three. If they're older than three and not in kindergarten, then I use the FDLRS program. When they're in school, it's the school.

How have you maintained your relationship with community resources? Is there a point person here? Is it with those brochures that you informed me of?

Yeah, there's no point person. The social worker was hired to work with adolescent physicians in the HIV program. He's just a great resource of all the community resources

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so, when I really have a problem, I call him.

How have you been able to increase parent awareness of developmental delays and disabilities? How do you educate them as they are with you?

In what way?

Say I come in with my child and you notice toe walking or low tone...how would you educate me about the issue and what I may need to do at home as well?

I don't know that I would...because I don't know what's going on yet.

Can you think of an instance where you had known what's going on?

Say that there's a language delay...we're part of the Reach Out and Read program so I have a grant to give out books at every well-child visit. I really emphasize even more than normal, reading to them. If they indicate wants by pointing, I tell the parents to verbalize the words several times before they give the child what they want by pointing. In the rooms, there are brochures they can take for ADHD and stuff like that.

You didn't indicate the usage of the developmental screeners. Why is that?

Other than what those questions are on each well child that are age relevant developmental questions...there is the Ages and Stages I think it is, and they do that down at 17 Davis. We've tried to do it here and we elected not to. It's kind of a unique situation where it's like I was with my partner and we work exclusively with medical students...seeing patients and then making sure their work is correct and they're generally much slower. So, it wasn't a feasible situation to turn over the rooms quick enough.

Appendix G (Continued)

So, time was an issue? Yes...and I can't even, in terms of support staff. I have one nurse to do everything. So, I can't even ask her to do that.

You did not indicate that you were able to determine the cause of delays or consult with the appropriate professionals.

Time and accessibility are issues. Other professionals are really hard to get a hold of. I don't blame her, that's just how it is. She's really the one person that I know I can get a hold of.

Your partner?

[Doctor]. She's really the only one that I know. There is another one who deals with autism, but I can't remember his name. His program is entirely pay upfront...no insurance. So, none of my patients can really afford it. It's like five hundred something dollars for the initial assessment.

You didn't indicate that you've been able to assist families with interpreting reports or feedback from other practitioners. Was this a statement that doesn't really occur for you? Do families bring in reports from someone else and ask you to explain it?

I will get whatever assessment that's been done across the street. So I get that and sometimes they will bring in school performance report cards or letters from teachers and the concerns that they have. In terms of some of the various developmental testing that gets done, I don't feel extremely confident in being able to interpret it and discuss it intelligently.

Would that information come from child development setting?

Appendix G (Continued)

That or the school setting.

Ok. Here, you indicated that you were not able to develop a strategy for providing periodic screening. Is that accurate because we just talked about how you typically screen kids?

I guess I was thinking more of like the formal Ages and Stages and stuff like that. Other than the set of, I think it's about nine questions on the well-child check, then I guess that's it.

Do you guys have a protocol for that?

It's just a form and the questions are appropriate for each age.

Another one that you indicated is that you are unable to present screening results to families using a culturally-sensitive or family-centered approach.

I didn't understand that.

For example, what if you have a family that did not speak English? Or, what if you had a family who just did not understand you and you're trying to make it more concrete for them? How do you approach those instances when you have to really help them try to understand what's going on?

Well, in terms of the language barrier, that's a difficult one because none of my staff speak Spanish. But, there are receptionists that we can find to help translate, which I know is not the best situation. I also draw a lot of pictures to help them understand also when they apply.

Give me an example of something you may have drawn for a parent to help them

Appendix G (Continued)

understand.

In the developmental realm or...

Anything in general.

Asthma. I'll draw the lungs and the airways and how they constrict. I'll draw reflux.

And how about developmental pictures?

That's about it. I had a family from Sierra Leon and they spoke French. We used Google Translation to communicate with the patient. You can put it in English and it will translate it to whatever language.

So, your patient would write their response in their language?

Yes, and it would translate to English. It made it a very long visit [laughing]. My student showed me that.

Ok. There were a lot of barriers listed at the end of the online survey. You indicated which ones remain barriers for you. One stated obtaining reimbursement for preventive services. You're able to do this. How did that come about within this environment?

You're talking about reimbursement for well-child checks?

Yes.

I verify the patient's insurance. Well, they're supposed to before the patient comes in. Then we have the billing slips and it gets submitted to the insurance. I don't know how much we collect on it but we certainly file for those claims.

Now, when we say well child I want to make sure that I understand. Would that be

Appendix G (Continued)

considered preventive?

Yes, like immunizations, we do that.

Ok, I wanted to make sure. Can you list the types of preventive services?

Sure. The first one technically is at the two week visit, but we usually see kids before then out of the hospital. Then two months, four months, six months, nine months, one year, fifteen months, eighteen months, and then two years and every year thereafter.

And you said immunizations are one of the preventive types of care?

Yes. There have just been some issues with immunization reimbursement that it doesn't even cover our cost some times. If the immunization cost is one hundred dollars and the insurance gives us one hundred dollars back, that doesn't cover any overhead such as the cost to administer, space for refrigeration, etc.

We've gone over the other barriers in our conversation. We talked about the screening tools and you stated that you don't particularly use any at this site

because you refer out...and of course you can't score them if you don't have them.

We also talked about the community resources and you indicated to me that you use two in particular, but you also have the social worker for additional help.

He's not technically for us, I just use him for emergencies.

Ok. Then assigning office staff is difficult because of limited staff, limited time, and...

Limited space.

...limited space.

Appendix G (Continued)

Yes, I only have two rooms.

Financing the cost of standardized instruments is not an issue because you don't use them here. Are there any barriers that you've run into that have prevented you from doing your job more effectively that I have not mentioned?

That you haven't mentioned? Those are the biggest ones. My time...I have to see the patient so I can turn over the room. I have 30 minutes for a well-child check and that includes my student going in and getting the history and the physical, and then coming out to present the patient to me. I then go back and repeat the exam, my nurse comes in and administers vaccinations, and then there's a dialogue...but then you're behind.

That sounds like a hectic schedule that you deal with daily. Well, this interview has been very informative. Thank you.

Appendix G (Continued)

Participant Number: 6

Interview Date: 4/23/07

Key: **Interviewer's responses in bold**, pediatrician responses in normal typeset.

What do you do and how often do you work with children and families on a weekly basis?

I'm an in-patient doctor. Pediatricians refer to me. I see maybe, at most, twenty patients a day which is eighty to one hundred patients per week. I am a Pediatric Hospitalist.

Children don't come to us for developmental issues. They typically come for something else. Usually, it's just part of our physical intake form. You know it asks if a two month old is tracking, etc. So, for every patient that comes in, we do a post medical history, family history, etc. Then from that, if we pick something up then usually the referral is to neurology or the developmental specialist, [doctor], where we have Early Steps. So depending on the level of disability or developmental delay, we'll refer them to say, Early Steps, so they can get the intake here in the hospital and be sent out for outpatient work.

So, in summary, children come to you for various reasons, but you have an intake form and you look at past medical history, family history, feeding history, gestational information...every type of history to gain further information.

Yes, birth history and everything. But one of those is a full developmental history and then we do a physical exam. Our residents also help with this.

You indicated on the online survey that you have been able to keep up-to-date about developmental issues, risk factors, screening techniques, and community resources

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to assist with consultation, referral, and intervention. How have you done this?

I attend conferences, read articles, and attend Grand Rounds. We have resources in the hospital such as a social worker. Also, I adopted a child with special needs. It takes compassion to have a child with concerns.

You did not indicate that you present screening results to families using a culturally-sensitive and family-centered approach. Tell me your thoughts about this particular topic. For example, how have you worked with a family that had limited education or did not speak English?

I draw a lot. I'm a visual person so I use drawings to help them understand. For example, if someone has a urinary tract infection, I will draw the kidneys and explain how they function to help the parent understand. We also use Spanish handouts that we give the families who speak Spanish. Some of our residents may be able to help translate. We also have Pastoral Care for families who are experiencing a very tough time with their loved ones within the hospital.

I see...you also indicated that you refer children with developmental delays in a timely fashion to the appropriate early intervention or early childhood programs within the community. Please explain the process you have implemented in order to do this in a timely fashion.

We have a protocol for testing for disability or developmental delay. We have our physical intake form and we collect information regarding past medical history family

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history, feeding, gestation history, birth history, and a full developmental history. This is very thorough. If any concerns are found, we refer immediately to different resources as needed such as parent programs, neurology, Early Steps and FDLRS are good Speech therapists and Genetics as well.

You also indicated that you are able to determine the cause of delays or consult with the appropriate healthcare professional or consultant for determination. How do you go about doing this?

This doesn't really happen in this setting. A time crunch makes it difficult to do this because there's difficulty reaching the patients' doctors.

How about within the school system?

I've consulted with teachers and school nurses at times regarding children.

You didn't indicate that you have acquired the skills needed to administer and interpret valid and reliable developmental screeners. Does this occur in your setting?

No.

Would that be the same answer for providing a strategy for periodic screening in the context of office-based primary care?

Yes.

How about maintaining relationships with community-based resources and coordinating care with them through the medical home. Does this happen within this setting?

Appendix G (Continued)

No it doesn't.

You indicated that you have been able to increase parents' awareness of developmental disabilities and resources for intervention. Please explain how you have been able to do this.

I explain the best I can what the concerns are and we have several resources such as Early Steps and FDLRS and others that we refer to as concerns arise.

You indicated that you have been able to assist families with interpreting reports or feedback from other practitioners. Please explain how this may occur at your site.

I put myself in their place. Before I was a doctor, I think about how I would want it interpreted. I see parents and they are waiting for the doctor. When I was a patient, I held on to everything the doctor said. I help explain lab results to parents but I don't always get reports. But as a primary care physician, I've helped patients read speech language reports and other reports. I just give them the bottom line.

I understand. Ok, I am going to read through a list of barriers and I will start with the barrier that you indicated that you've overcome within your setting. This barrier is referring families to community resources for intervention. You did not consider this to be a barrier. Why is that?

Because we have access to a social worker and pastoral care to talk to families and comfort them.

The other barriers I will briefly read through but I realize that they may not apply to your hospital setting. One barrier is assigning office staff to assist with

Appendix G (Continued)

developmental surveillance. Does this occur?

No.

How about financing the cost of standardized instruments...Does this occur in your setting?

No.

Obtaining reimbursement for preventive services...Does this occur in your setting?"

No.

Administering validated screening tools...Does this occur?

No.

Scoring validated screening tools?

No.

Are there any barriers that I have not mentioned that make it difficult for you to serve children and their families?

Yes...Providing hospital care to illegal migrant workers. Medicaid pending pays for illegal aliens to get care in the hospital, but they don't get Medicare. Then there's the issue of primary care, which has to see several patients per day to keep their practice going...and the insurance companies don't pay.

Alright. Well, if that is it, I really appreciate your time speaking with me given your hectic schedule. Thanks so much.

Appendix H

Audit Trail

Participants	Interview	Criteria for Inclusion in Interview
Participant One	Interview Date: 3/21/07 Time Frame: 1 hr 30 min Setting: Face-to-Face Interview	Reported following 9 AAP Guidelines on Online Survey
Participant Two	Interview Date: 3/22/07 Time Frame: 1 hr Setting: Face-to-Face Interview	Reported following 8 AAP Guidelines on Online Survey
Participant Three	Interview Date: 3/29/07 Time Frame: 1 hr 20 min Setting: Face-to-Face Interview	Reported following 8 AAP Guidelines on Online Survey
Participant Four	Interview Date: 4/6/07 Time Frame: 1 hr Setting: Face-to-Face Interview	Reported following 7 AAP Guidelines on Online Survey
Participant Five	Interview Date: 4/17/07 Time Frame: 55 min Setting: Face-to-Face Interview	Reported following 4 AAP Guidelines on Online Survey
Participant Six	Interview Date: 4/23/07 Time Frame: 45 min Setting: Phone interview (could not meet face-to-face due to scheduling conflicts; preferred phone interview)	Reported following 5 AAP Guidelines on Online Survey

Appendix I

Bracketing Interview

I am Kahlila Mack, school psychology doctoral student at the University of South Florida. I currently work with elementary, middle, and high school students within a large county in the state of Florida. I am originally from an urban city in New Jersey and I moved to Florida after deciding to pursue higher education at a private college. After graduating with a bachelor's degree in psychology, I was accepted into the University of South Florida's school psychology program.

During my matriculation through USF's graduate program, I have had numerous experiences working with young children and their families. My first experience was as an assistant supervisor of a summer reading program created for families within the local community. The focus was to assist the parents with learning strategies for engaging their children in reading fluency and comprehension. I helped to supervise undergraduate teacher education student volunteers who, along with myself, worked directly with the families to discuss and model ways to enhance their children's reading skills.

School practicum assignments were additional experiences that I've had with young children during my early graduate career. These experiences gave me my initial understanding into the needs of young children (i.e., primarily kindergarten through first grade) within the school setting. I typically observed and interacted with these children in a manner that allowed me to begin learning to build rapport with the children, assess the children's academic and behavioral skills, implement interventions, and consult with parents and a variety of school staff.

Appendix I (Continued)

My next experience working with young children came with my employment as a graduate student within the public school district. During this time, I worked with Child Find on a Pre-K assessment team which completed assessments of children three to five years old who were suspected as having developmental concerns. This was a multidisciplinary team which consisted on a speech pathologist, social worker, and school psychologist. Each member conducted evaluations within their specific expertise in an effort to produce a wholistic picture of the child's concerns and needed interventions. Several children were referred to the team after attending a developmental screening offered free to all families who attend. I, along with other educators and community agencies, worked these monthly screenings. This experience provided me with additional insight on the developmental concerns of young children and the various resources available for intervention planning and development.

As I worked with Child Find and at the monthly developmental screenings, I simultaneously worked at a local agency called the Early Intervention Program (EIP). This setting provided me with experiences that allowed me to collaborate with other disciplines such as developmental pediatricians, service coordinators, and other school psychologists. At EIP, young children, birth through three years, were referred to this site as well to assess their developmental concerns.

After these profound and enlightening experiences, I worked at a local mental health institute where I was matched with families of young children having developmental disabilities and displaying challenging behaviors. During this time, I worked with the children within their home and preschool settings to assist with

Appendix I (Continued)

developing interventions with their caregivers. Working with families in such a manner gave me an even closer look into the daily struggles that they often face. During this time, I was challenged to go beyond my textbook knowledge and think creatively in an effort to help the families I had now become a part of.

My previous experiences have shaped the way I view young children and families to this day. I am now on my school psychology internship at two elementary schools and two alternative schools for middle and high school students who have been expelled from the public school system due to frequent and/or severe behavior concerns. Although there is a significant difference between these two types of schools, I have begun to see a trend emerge. After reviewing several alternative school students' school records, I have noticed that many of their early school years (e.g., kindergarten and first grade) consisted of academic failure. The school progress notes and psychology reports that I reviewed for these students' later school years continued to show academic concerns and, oftentimes, coexisting behavior concerns.

This has caused me to ask the question, "Did my alternative school students show any signs of delays, disabilities, or other concerns before they entered the school system?" If so, "Could all of this have been prevented?" There are numerous reasons why a child may not show improvement after receiving academic and behavioral interventions within the school system (e.g., frequent school moves, frequent absences, etc.). However, my interest had been "sparked" as I continued to ponder on ways families of young children who are at risk for developmental delays and disabilities could be assisted as early as possible through a collaboration of professionals. I had the honor

Appendix I (Continued)

of working among many great professionals who service young children effectively, despite the obstacles that make their job challenging. I was interested in learning about how they have thought “outside the box” in an effort to provide excellent care to young children and families. I also was concerned about how we all, as multiple disciplines, could continue to collaborate in an effort to help children and families. Therefore, my research begins with a discussion of general pediatricians, whose area of discipline often has the most interaction with young children and families as compared to other disciplines.

About the Author

Kahlila Genese Mack was born and raised in Paterson, New Jersey. She obtained her Bachelor's degree in Psychology from Bethune-Cookman College, now Bethune-Cookman University. She graduated from the University of South Florida and received her Doctoral degree in School Psychology.