ABSTRACT

Title of Document: AN INVESTIGATION OF STATE-LEVEL CHILD FIND AND PUBLIC AWARENESS CAMPAIGNS TO PROMOTE EARLY INTERVENTION TO THE MEDICAL COMMUNITY

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The Individuals with Disabilities Education Improvement Act requires States, through their Child Find Program, to locate, evaluate, and provide services to all children with delays. The purpose of this research was to investigate what the States are doing to promote Child Find to the medical community, how they evaluate the effectiveness of their efforts, and what, if any barriers prohibit these efforts. Three data collection methods were used: 1) an analysis of each State's policy as it relates to Child Find and the medical community, 2) an analysis of public awareness plans as they relate to Child Find and the medical community, and 3) a survey sent to each of the Part C lead agency coordinators in each State and US territory investigating Child Find efforts to the medical community. The results of this research reveal that most States have vague or ambiguous objectives in their policies related to Child Find and public awareness to the medical community. However, States' public awareness plans contain more detail about these objectives. The majority of States are working in collaboration with the medical community, as 85% had a member of the medical community serving on the State Interagency Coordinating Council. Ninety-one percent of the respondents reported their State collects data on how many referrals to early intervention they receive each year, and 100% of the people who responded reported collecting data on where these referrals come from. Only 56% collect referral data from the NICUs; however 94% collect data on referrals from other medical related institutions. Seventy percent have a public awareness plan and 53% routinely collaborate with the Local Education Agencies (LEA) on the effectiveness of this plan. In spite of plans, policies, and collaborative efforts, the States are still experiencing barriers in their efforts to reach out to the medical community. Lack of staff, lack of time, and difficult accessing the medical community were the three most frequently cited barriers. Limitations of this research, as well as suggestions for future research and practice are presented.

AN INVESTIGATION OF STATE-LEVEL CHILD FIND AND PUBLIC AWARENESS CAMPAIGNS TO PROMOTE EARLY INTERVENTION TO THE MEDICAL COMMUNITY

By

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Dissertation submitted to the Faculty of the Graduate School of the
University of Maryland, College Park, in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
2006

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Preface

I have worked in the early intervention system and the preschool special education system for nearly seven years. During this time it became clear to me, through various instances and family stories that many infants and young children were not being referred to early intervention services. During the summer of 1999, I was an educational evaluator for the local Child Find program. We evaluated children between the ages of three and five for early intervention service eligibility. I encountered some children whom I knew would qualify based only on my conversation with the family, before I even began to test the child. I would ask these families when they first became concerned about their child's development. The answer was always the same. The family usually became concerned around the 18-month age, and the advice from the pediatrician was always the same "wait and see". As a service coordinator for the local infants and toddlers program, I encountered the same situations, however it is now 2006. I remember speaking to a mother about when she first noticed something was wrong with her son's legs. She explained to me she discussed her concern with the pediatrician who told her to wail until he begins walking. The mother, after coming to the NICU follow-up clinic decided against her pediatrician's advice and wanted a physical therapy evaluation. The evaluation revealed a significant size difference between the child's legs and atypical gross motor development thus qualifying the child for early intervention services. After nearly a year of physical therapy services including stretching techniques, the little boy's leg length discrepancy is decreasing and his motor skills have improved dramatically. Families know their child better than anyone else, and they are frequently the first to notice a problem. The pediatrician is often the first one the family goes to with their concern. This transaction between the family and the pediatrician could result in a referral to early intervention or a "wait and see" approach. Granted, for some children, waiting and seeing if they catch up isn't always problematic, however this decision should be left up to the family. It is the pediatrician's responsibility to inform the family of the availability and efficacy of early intervention services. It is the State's responsibility to educate the pediatrician on the availability and efficacy of early intervention services. Somewhere, a single or multiple problems lie either within the educational or the medical system, or perhaps both, that ultimately result in children not being referred to a program that would improve their development; a program they have the right to benefit from.

Acknowledgements

I would like to acknowledge the special people who helped me along the way and make this dissertation a reality. First, I would like to thank my committee, Drs. Paula Beckman, David Cooper, Elisa Klein, Brenda Hussey-Gardner, and Joan Lieber, whose support and advice were much appreciated. I would especially like to acknowledge Joan Lieber for her support, encouragement, and patience.

I would also like to acknowledge my family for their belief in me; to my parents, Judy and Dave Fulton who gave me the strength and confidence when I needed it the most, and were always there to pick me up when I would fall along the way; to my aunt, Elizabeth Anderson who believed in me when I stopped believing in myself, and gave me continual support along the way; to my Tech. Ed. Department, a.k.a. my sister and best friend Carrie Miller without whom JADE would have never been possible; and especially to my fiancé, Richard Telesco, who loved me at my worst, saw the light at the darkest moment, and who put up with me when I was unbearable, and still wants to marry me! If I could put all of these names on my degree, I gladly would because it took the combined strength of everyone for me to finally reach my goal!

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Chapter 1: Introduction

Early intervention has not been entirely embraced or uniformly supported (Meisels & Shonkoff, 2000) although research exists that document its long term effectiveness even on children born prematurely (McCormick et al., 2006). The incidence of preterm birth increases every year, and the impact reaches beyond the health and medicine field, and into the field of early intervention. Without a collaborative effort between the medical field that saves the lives of these infants, and the educational field that provides the services to these infants and their families, the field of early intervention will continue to struggle in its efforts to promote the development of young children.

Incidence and Risks from Preterm Birth

Each week in the United States, 78,054 babies are born. Of these babies 5,904 are born with low birth weights and 8,985 are born preterm. Low birth weight (LBW) is categorized as 2500g – 1500g; very low birth weight (VLBW) is categorized as 1499g – 1000g; and extremely low birth weight (ELBW) is less than 1000g. Preterm birth is less than 37 completed weeks of pregnancy and less than 32 weeks completed pregnancy is considered very preterm. Illness or morbidities increase with decreasing gestational age and birth weight. Babies who are born too soon are often times born too small. Even though the causes of preterm birth and low birth weight may be different, there is significant overlap within these infant populations (www.marchofdimes.com/peristats; www.cdc.gov/nchs/faststats/birthwt.htm).

The survival rate for premature infants has dramatically increased in the past decade. With today's more sophisticated technology, babies born prematurely are being kept alive at an increasing rate. To be born prematurely, or having low birth weight, is an immediate developmental setback, often compounded by multiple medical complications which often require invasive and prolonged treatment in the neonatal intensive care unit (NICU). Although the survival rate has increased for preterm babies, so has their risk for developmental disabilities (Hussey-Gardner, McNich, Anastasi, & Miller, 2002; Sykes et al., 1997; Wood et al., 2000).

The earlier a baby is born, the greater the likelihood of medical complications which may qualify the infant for early intervention services under Part C of the Individuals with Disabilities Education Improvement Act (IDEA). Many of these medical diagnoses automatically qualify the infant for services under what is called high probability, or conditions of established risk. States are required to provide automatic eligibility to infants with a high probability diagnosis. However, each State can determine which medical conditions qualify an infant under this category. According to the National Early Intervention Longitudinal Study (NEILS) a significant number of children in early intervention had compromised birth histories, including LBW, prematurity, and a history of care in an NICU (Spiker et al., 2004).

It is well documented that children born with low birth weight are also at risk for developmental disabilities, namely, cerebral palsy, mental retardation, behavioral and attentional difficulties, sensory impairments, and general developmental disabilities (Sykes et al., 1997; Weindrich et al., 2003; Wood et al., 2000). These disabilities may also qualify a child for early intervention services.

The prevention of disabilities in preterm infants continues to be one of the most important challenges in medicine (Wood et al., 2000). With the changing role of medicine in society, and the continuous debate over health care, the increasing survival and neurodevelopmental outcomes of these low birth weight infants has emerged as an area of great interest to the medical field (LaPine, Jackson, & Bennett, 1995) as well as the field of early intervention.

Children are born every day that would benefit from early intervention services. Learning begins immediately at birth and involves the interaction between the child, and his or her environment. The sooner potential risks are identified, the greater the likelihood of minimizing or even eliminating existing problems or preventing future ones (Shackelford, 1994a). Since preterm babies often spend a significant amount of time in a NICU, health personnel are often the first people outside of the child's family to suspect or identify a delay (Shackelford, 1994b). Regardless of whether or not an infant has spent time in a NICU, physicians are often the first professionals to see the infant. For this reason, the medical community, in addition to the parents and family, has the first opportunity to make referrals to the early intervention system (Solomon, 1995).

However, health personnel may not be aware of early intervention in their community, and thus may not be able to educate families about early intervention options. The federal government has recognized the need to educate the medical community about the importance and benefits of early intervention by making a Child Find and public awareness component a significant part of Part C early intervention mandates.

Role of the Federal Government

The federal government has played a defining role in the evolution of early intervention. In 1968, the Handicapped Children's Early Education Program was created within the Bureau of Education for the Handicapped to develop model programs and practical materials in order to show local communities, families, and professionals how early intervention could support children and their families. In 1975, with the passage of P.L. 94-142, the Education for All Handicapped Children ACT (EAHCA), States were encouraged to provide services for children with disabilities starting on their third birthday (Wolery & Bailey, 2002). This was the beginning of early intervention.

In 1986, Congress recognized the importance of early intervention for young children with disabilities and passed the P.L. 99-457, the Infants and Toddlers with Disabilities Act. This amendment was originally added to EAHCA as Part H. Part H provided incentive grants to the States that provided special education and related services to children with disabilities from birth through age 2. Later, in 1997, this amendment became Part C when the Individuals with Disabilities Education Act (IDEA) was reauthorized.

As described in the IDEA regulations, each State is required to develop and implement a comprehensive Child Find system. Child Find must include policies, practices, and procedures for promoting referrals for evaluations and assessments to determine a child's eligibility for early intervention if the child is between the ages of 0 – two, or preschool special education if the child is between the ages of three and five. In addition, States must also implement methods and procedures that health care providers, parents and other individuals and agencies can use to make these referrals to early intervention or preschool special education. Child Find consists of a range of activities and initiatives used to identify these children and to increase awareness and understanding of the value and the benefits of early intervention (Dunst, Trivette, Appl,

& Bagnato, 2004). These methods and procedures for educating the community about early intervention are typically referred to as public awareness efforts or campaigns.

In the 2004 IDEA amendments, a new population of potential early intervention recipients was added to the requirements for public awareness campaigns. The public awareness campaigns as described in the Child Find criteria, should target all primary referral sources ". . . especially hospitals and physicians, of information to be given to parents, especially to inform parents with premature infants, or infants with other physical risk factors associated with learning or developmental complications of the availability of early intervention services . . ." (20 U.S.C. 1435(6)). Hospitals, especially prenatal and postnatal care facilities, and physicians are listed as primary referral sources.

With this new component, States must establish a way of reaching out specifically to the NICU personnel that take care of premature and sick babies, in addition to the general medical community. The States are responsible for educating and informing the pediatricians, neonatologists, nurses, and other personnel providing services to the babies in the NICU of the benefits and importance of early identification, as well as how to make the necessary referrals into the early intervention system.

To address the federal regulations, each State develops its own rules and regulations related to early intervention. There are 16 components that are mandated by IDEA, Child Find being one of them, as well as an accompanying set of regulations. However, States are allowed considerable flexibility in program implementation (Scarborough et al., 2004).

Reaching the Medical Community

In spite of the Child Find provisions of the law, there is evidence that States have not been effective in their efforts to promote the importance of early intervention and the necessary procedures for making referrals into the early intervention system to the medical primary referral sources. According to Blackman, Healy, and Ruppert (1992) pediatricians' awareness, participation, and training in early intervention were three of the main categories listed as obstacles to implementing PL 99-457.

In the past, pediatric education consisted of little training in the area of child development and disabling conditions. In 1963, the Joint Committee on Pediatric Research, Education, and Practice first described the problem (Steigman, 1963). Later in 1978, the Taskforce on Pediatric Education was established to develop a curriculum to provide pediatric residents with the fundamental skills and knowledge related to the assessment process and the management of children with disabilities (Blackman, Healey & Ruppert, 1992).

There is a solid body of research documenting problems with physicians' training in and awareness of early intervention dating back over 40 years. Pediatricians do not receive much training in early intervention during their residency programs, and many are unfamiliar with federal legislation related to early intervention. However research also indicates that the medical community is interested in learning more about early intervention services (Helm & Shishmanian, 1997; Scott et al., 1993; *Survey of Connecticut Pediatricians*, 1997).

In addition to the problems documented by the medical community itself, federal monitoring has highlighted the difficulty in reaching the medical community. The U.S. Department of Education's Office of Special Education Programs (OSEP) conducts monitoring efforts and generates monitoring reports to address areas of concern. For example, in 1999, OSEP conducted a review of Maryland's compliance with the implementation of IDEA. OSEP indicated in Maryland's Monitoring Report that several areas needed improvement. A letter written to the Maryland State Superintendent on July 26, 2001 stated that one of the areas in need of improvement was targeting public awareness efforts for physicians. A public input meeting was held to determine what the barriers were to the process of referring infants and toddlers. During the public meeting, concerns were raised about the failure of primary referral sources, namely physicians, in referring eligible children to the early intervention system in a timely manner.

In another example, a letter was written to the District of Columbia's Superintendent dated June 18, 2002, as part of OSEP's 2002 overview of the District of Columbia's compliance with the implementation of IDEA. The letter stated that the District's Child Find and public awareness activities were in noncompliance. During their public input meeting, the same concerns that were raised in Maryland were noted; specifically that public awareness materials were not available at all primary referral sites, and the physicians were not making referrals to early intervention in a timely manner. Further, physicians were not always aware of early intervention services. The report clearly stated that the District had not ensured their public awareness activities were adequately informing primary referral sites about early intervention.

Statement of the Problem

Children do not grow and develop in isolation; no single element is entirely damaging or absolutely facilitating for children. Child development has numerous contributors at various levels of the child's ecology (Sameroff & Fiese, 2000). Sameroff and Fiese describe a transactional model which serves as the theoretical foundation for this research. In the transactional model, a variety of factors affect the child's development. The child's development results from the continuous dynamic interactions of the child and the experiences provided by his/her family as well as the interactions in the social context. The child's outcome is a product of complex function of the interplay of the child and his/her environment over time. For example, in addition to the parent's beliefs and practices affecting the child's development, additional variables, beyond the scope of the child's family, can also influence a child's development. For the purpose of this research, more removed factors such as the relationship between the family and the pediatrician, the relationship between the pediatrician and the local or State Child Find efforts will be addressed, and the relationship between the State Part C lead agency and the local Child Find programs.

To date, there exists limited nation-wide research documenting what the States are doing to promote early intervention to medical primary referral sources. Many of the young children who spend time in the NICU automatically qualify for early intervention services due to high probability characteristics. In fact, 38% of children in early intervention spent time in an NICU after birth. This is 10-20% more frequent than that of the general population. It is also interesting to note that 20% of the children in early intervention who were born with normal birth weights also spent time in an NICU after birth (Spiker et al., 2004). However it is not known if these children are being referred before leaving the hospital. It is also not known if the parents are being educated about their options in early intervention by the medical personnel who work with the children in the NICUs.

Moreover, it appears that physicians have both a lack of training and a lack of knowledge about early intervention. Referrals are not being made to early intervention for a variety of reasons including a lack of awareness about early intervention services, uncertainty of the efficacy of early intervention and a lack of knowledge about eligibility criteria (Helm & Shishmanian, 1997; Scott et al, 1993).

Purpose of the Research

It is the responsibility of each State to implement a public awareness campaign to target and inform the general public about early intervention. It is also the State's responsibility to educate primary referral sources including the medical community. It is essential that we know what the Part C programs are doing to fulfill this mandate.

The purpose of this research is to survey each State and U.S. territory on their practices to promote early intervention to medical primary referral sources, to learn how each State and territory evaluates the effectiveness of these practices, and to identify barriers that prohibit the provision of these services. By identifying effective practices and ameliorating barriers, it is hoped that we will be able to foster a collaborative relationship with the medical community by increasing the number of referrals to early intervention and increase the number of children and families who could benefit from these services.

In order to address these purposes, I will investigate the following research questions:

1. What are the Part C lead agencies doing to promote Child Find and early intervention to the medical community in general and more specifically NICU personnel?

2. How are Part C lead agencies evaluating the effectiveness of these public awareness campaigns?
3. What are the current barriers to promoting early intervention to the medical community?

Chapter 2: Review of Literature

In 2003, there were 499,008 babies born preterm in the United States. This number represents 12.3% of all live births, and has increased from the 480,812 babies born preterm in 2002. Between 1993 and 2003, there was a 13% increase in the number of infants born preterm (www.marchofdimes.com/peristats). According to current research from the NEILS (Scarborough et al.,2004) there is a significant number of children in early intervention who spent time in an NICU. It is well documented that preterm children are at an increased risk for developmental delays (Taylor, Hack, Klein, & Schatschneider, 1995; Wood, Marlow, Costeloe, Gibson, & Wilkinson, 2000; Weindrich, Jennen-Steinmetz, Laucht, & Schmitd, 2003). For this reason, it is not surprising that LBW, prematurity, and their sequelea are included in many States' eligibility definitions for early intervention. For these infants to receive the early intervention they are entitled to, they must first be referred to the infants and toddlers program in a timely manner.

After being discharged from the hospital after birth, pediatricians are often the first professional a family sees, regardless of whether or not time was spent in an NICU. This places the pediatrician is in a unique position to make timely referrals for children suspected of having a delay. If an infant has spent time in the NICU, the neonatologist, who is a pediatrician specializing in the care of preterm and sick newborns, is oftentimes the infant's first pediatrician.

In either case, the medical community providing care for infants should have current information on early intervention in order to educate parents of their rights and options. However, the goal persists of finding and referring children at the earliest possible age; early intervention requires early identification (Meisels, 1991). In this chapter I provide an overview of the literature related to physicians' awareness and knowledge of early intervention as well as barriers that prohibit the provision of timely referrals into the early intervention system. Also included in this chapter is research on pediatric training in early intervention during residency programs. Finally, I review federal and State legislation related to early intervention and public awareness/Child Find strategies to educate the medical community.

Literature Search

When gathering information pertaining to public awareness strategies to promote early intervention to medical primary referral sources, and information related to physicians' awareness of and training in early intervention, I did electronic and ancestral searches for the years 1963 to 2005. I choose these years to address the most current research findings pertaining the topic as well as to understand the evolution of pediatric training in early intervention. The electronic databases I used included PsychINFO, EBSCO, Medline, PubMed, and ERIC. The relevant keywords I used included 'premature', 'low birth weight', 'outcome', 'NICU', 'early intervention', 'pediatrician', ' public awareness', 'high probability', 'disability', and 'referral'. I conducted an ancestral search of relevant periodicals related to this topic. I reviewed the indices of periodicals in order to locate relevant research-based articles pertaining to the topic. The periodicals included: *Journal of the American Medical Association, Pediatrics, Infants and Young Children, Journal of Child Psychology and Psychiatry, Journal of Early*

Intervention, Topics in Early Childhood Special Education, Journal of Developmental Behavioral Pediatrics, Journal of Pediatrics, and *Exceptional Children.*

This search produced nearly 50 articles. I eliminated articles that focused on topics such as pediatric screening issues, and pediatric referrals to other organizations such as Head Start. In this review of literature, I critiqued five research articles related to pediatric training and education as well as two research articles related to current information on early intervention from the National Early Intervention Longitudinal Study (NEILS) data. The remaining articles were not research oriented and were used to provide supplemental and supportive information related to public awareness to medical primary referral sources. Due to the limited amount of research that exists on the topic, methodological rigor was not an eliminating factor.

The literature documenting the training pediatricians receive in early intervention dated back over 40 years. It documents the training pediatricians receive in their residency programs, and what they currently know about early intervention, as well as what barriers prevent them from making timely referrals into the early intervention programs (*American Academy of Pediatrics*, 2004; *American Academy of Pediatrics*, 2003; Helm & Shishmanian, 1997; *Survey of Connecticut Pediatricians*, 1997; Scott et al., 1993). The search also revealed research on various model demonstration programs to promote collaboration between the medical and educational communities (Garland, Gallagher, & Huntington, 1997; Kaplan-Sanoff & Nigro, 1998; Solomon, Clougherty, Shaffer, Hofkosh & Edwards, 1994).

I also located articles related to generic marketing strategies to promote awareness of early intervention (Fugate & Fugate, 1996; Smith & Klonglan, 1990).

Current research on the National Early Intervention Longitudinal Study (NEILS) data also provided valuable information (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Scarborough et al., 2004; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2004). There was a single article on birth defects registry as well (Farel, Meyer, Hioken, & Edmonds, 2003).

Surprisingly a paucity of research exists on what States are doing to promote early intervention to medical primary referral sources. I found only one article that investigated States' general public awareness plans, however, it was not specific to any one primary referral source (Berman & Melner, 1992).

Beginning with the theoretical foundation for this research, I review the literature pertaining to the topic in the following order. First, I provide information related to federal policies as well as AAP recommendations. Second, I review research on model demonstration programs and State projects as well as birth defects registry. Third, pediatric training and education follows. The article related to State public awareness strategies comes next. Finally, I conclude the review with current research from the NEILS data.

Theoretical Foundation

In the transactional model, developmental outcomes are a product of the combination of an individual and his or her experiences within the environment. Development is viewed as the product of the continuous dynamic interactions between the child and the experiences provided by the family, and the different social contexts (Sameroff & Fiese, 2000).

Many factors influence a child's development. These factors range from proximal variables such as child and mother interactions, to more distal variables such as the family's relationship with the pediatrician and the pediatrician's relationship with the State/local Child Find efforts. The most distant variable in this model is the State Part C lead agency. The transactional model emphasizes the complexity of development and the numerous variables that influence child development. Looking at these different variables, the transactional model is shown to highlight the relationships between these variables

For example (see Figure 1) if a child is born prematurely, this could contribute additional stressors on the relationship between the mother and the child, especially if the infant has to spend a significant amount of time in the NICU. The sequelea of preterm birth could cause the mother to be more aware and watchful of potential delays the infant may be experiencing. At the next level, is the relationship between the mother and the pediatrician. If the family addresses these concerns to the pediatrician, the pediatrician can have many reactions. If the pediatrician is aware and supportive of early intervention, and is familiar with the referral process, he/she can support the family in the decision to seek early intervention services. However, if the pediatrician is unaware or unsupportive of early intervention services because of insufficient Child Find efforts, the pediatrician may tell the family to "wait and see", and not make a referral to early intervention. At the farthest interactional level are the efforts and funding allowed by the Part C lead agency if promoting Child Find and early intervention at the local (or State) level.

Within this transactional model, the child's development is seen as a product of the continuous dynamic interactions between the child and the experiences within his or her environment. Sameroff and Fiese (2000) explain that "The child's outcome is neither a function of the initial state of the child nor the initial state of the environment but is a complex function of the interplay of child and environment over time (p. 142)."

One must look not only at individual ontogeny, but also the environment and how they interact to affect a child's development. In doing this, one is better able to address each level, the possible interactions between the levels, and how all these factors combine to affect the overall developmental outcome for these children.

Federal Policies and American Academy of Pediatric Policies

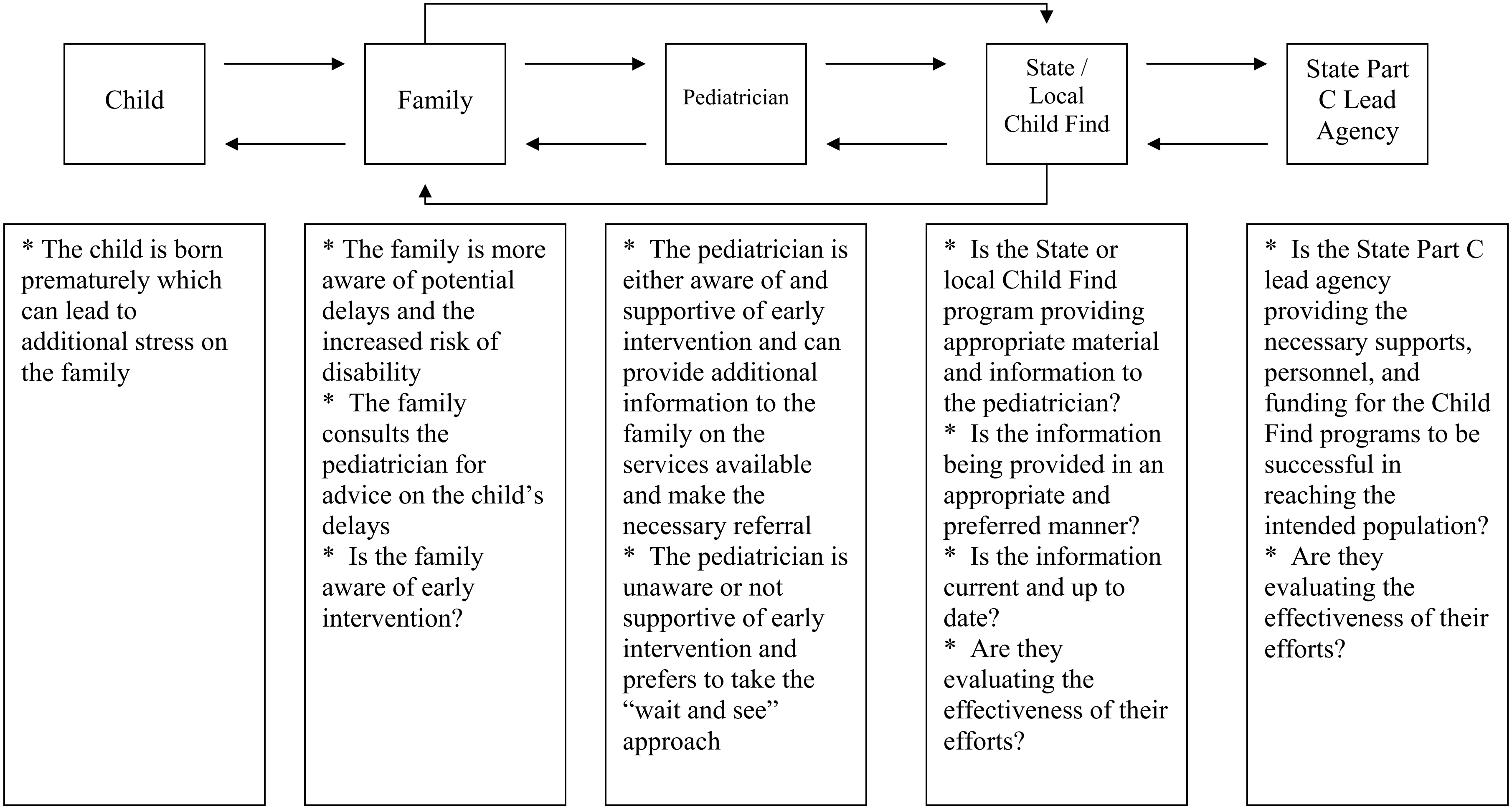
Federal Policies

States are required by IDEA to provide early intervention services to children who have conditions of established risk which is defined as "diagnosed, physical or mental condition which has a high probability of resulting in developmental delay " (20 U.S.C.1432 (5)(A)(ii)). Children who have conditions of established risk are automatically eligible for Part C Infant and Toddler services by virtue of their diagnosis regardless of whether there is a measurable delay (Shackelford, 2005). Examples of these conditions include "chromosomal abnormalities; genetic or congenital disorders; severe sensory impairments including hearing and vision; inborn errors of metabolism; disorders reflecting disturbance of the development of the nervous system; congenital infections; disorders secondary to exposure to toxic substances, including fetal alcohol syndrome; and severe attachment disorders" (34 C.F.R.303.16).

There is less agreement among other professionals, including policy makers, educators, and medical professionals regarding other conditions that could be included in this category. If conditions are not included in the established risk category, they are relegated to the biological/medical risk category and States are not required to provide services for children who fall into this category. For this reason each State has different conditions in their eligibility definitions for conditions of established risk (Shackelford, 2005). Regardless of how children qualify for early intervention, they must first be referred for further testing to determine eligibility to receive services.

Figure 1

Theoretical Foundation Conceptual Framework



* The child is born prematurely which can lead to additional stress on the family

* The family is more aware of potential delays and the increased risk of disability
* The family consults the pediatrician for advice on the child's delays
* Is the family aware of early intervention?

* The pediatrician is either aware of and supportive of early intervention and can provide additional information to the family on the services available and make the necessary referral
* The pediatrician is unaware or not supportive of early intervention and prefers to take the "wait and see" approach

* Is the State or local Child Find program providing appropriate material and information to the pediatrician?
* Is the information being provided in an appropriate and preferred manner?
* Is the information current and up to date?
* Are they evaluating the effectiveness of their efforts?

* Is the State Part C lead agency providing the necessary supports, personnel, and funding for the Child Find programs to be successful in reaching the intended population?
* Are they evaluating the effectiveness of their efforts?

As described in the Individuals with Disabilities Education Act (IDEA) 2004 amendments, States are required to identify all children with disabilities residing in the State, who are in need of special education and related services. These children must be identified, located and evaluated (P.L. 108-446; 118 STAT. 2677). P.L. 108-446 states that in order for this to happen, States must develop a comprehensive Child Find system. As part of this Child Find system, States must develop:

> A public awareness program focusing on early identification of infants and toddlers with disabilities, including the preparation and dissemination by the lead agency . . . to all primary referral sources, especially hospitals and physicians, of information to be given to parents, especially to inform parents with premature infants, or infants with other physical risk factors associated with learning or developmental complications of the availability of early intervention services . . . (118 STAT. 2747).

Hospitals, especially prenatal and postnatal care facilities, and physicians are listed as primary referral sources.

There is a noticeable absence of research related to what the States are doing to promote early intervention through Child Find and public awareness activities to these medical primary referral sources. However, the federal government plays a significant role in monitoring what States are doing, and by looking at the monitoring efforts by the federal government, we can better understand what the States are doing and how successful their efforts are.

The primary function of OSEP's Monitoring and State Improvement Planning (MSIP) Division is to assess the effectiveness of State and local implementation of IDEA. Each State has designated a lead agency to oversee the implementation of Part C early intervention services (see Appendix A for a list of each State and territory's Part C lead agency). OSEP, which is part of the Office of Special Education and Rehabilitative Services (OSERS) provides funding in the form of grants for which the lead agency applies. OSEP sets the guidelines States must include in their application for funding. OSEP is responsible for providing policy support, monitoring, as well as technical assistance to the States in order to assist in their implementation of Part C early intervention programs (23rd Annual Report to Congress, 2002).

In 1997, after the passage of IDEA, greater emphasis was placed on improving results. The Continuous Improvement Monitoring Process (CIMP) was created to incorporate strategies to encourage greater State accountability, and ensure public awareness and dissemination of early intervention services. The CIMP strategies fall under cluster areas that include Child Find and Public Awareness for Part C (23rd Annual Report to Congress, 2002).

According to the 23rd Annual Report to Congress on the implementation of IDEA, the CIMP process reports that State lead agencies are experiencing significant challenges in their administration of Part C programming. The Report to Congress documents that Child Find activities continue to present problems in some States. According to this report, seven States (35%) were in noncompliance for not having in place effective systems to ensure Child Find efforts. Nine of these States (45%) did not have effective public awareness programs to promote Child Find, and five (25%)

were not providing primary referral sources with information on Child Find. These States were not collaborating with physicians and other medical primary referral sources to ensure that referrals were made in a timely manner to the early intervention system (23rd Annual Report to Congress, 2002).

In addition to a comprehensive Child Find system, States are required to develop an interagency coordinating council (ICC). IDEA 2004 States that the ICC should be composed of, and include parents, members from the State legislature, Head Start, mental health, and Medicaid to name a few. A member representing the medical community is not required to serve on the State ICC.

The conditions and risk factors that a State may consider in defining its eligible population require interpretation by someone who has knowledge about genetics, neurodevelopment, chronic illness, and other medical issues. This reinforces the need for pediatricians to be a part of the State ICC (Blackman, Healy, & Rupert, 1992). However, few States have successfully integrated the health system, and the medical system with early intervention programs (*Survey of Connecticut Pediatricians,* 1997).

The ICC has many responsibilities including advising the State Part C lead agency and developing and promoting interagency agreements. For example, the Maryland ICC has an outreach committee. According to the mission statement, the outreach committee's responsibilities include developing strategies to improve general public awareness, particularly among physicians, and monitoring the system's success and barriers that affect Child Find activities.

The federal government mandates many components in IDEA including a Child Find / public awareness component. However, according to the 23rd Annual Report to Congress, many States have not yet developed and implemented effective systems to ensure Child Find efforts. Interagency Coordinating Councils are also required by IDEA; however a representative from the medical community does not need to be a part of the council. If the States have not entirely developed and implemented successful Child Find programs and have not successfully collaborated with the medical community, increasing referrals from the medical primary referral sources may prove to be problematic.

American Academy of Pediatrics' Policies

The American Academy of Pediatrics (AAP) is the professional organization for pediatricians and other physicians who provide medical care for children from birth through age 21. The AAP's purpose is to lobby for the rights of physicians and patients and to standardize care. The AAP consists of many committees including the Committee on Children with Disabilities.

The committee emphasizes the importance of the role of the pediatrician in early intervention, by providing many recommendations. Included in these recommendations is the pediatricians' role in referral to early intervention. The AAP clearly states that pediatricians need to be knowledgeable about State, federal, and local early intervention programs and requirements (*American Academy of Pediatrics*, 2001). According to their recommendations " . . . the pediatrician has an important role in the identification of children with established delays and the diagnosis of conditions with a high probability of developmental delay, which will qualify a child for [early intervention] (http://aappolicy.aappublications.org/cgi/content/full/pediatrics; 104/1/124, 1999).

The AAP's involvement in special education even predated PL 99-457. In 1965 the Joint Committee on Pediatric Research, Education, and Practice described the problem of a lack of pediatric training about children with disabilities. The Taskforce of Pediatric Education was established in 1978 to develop a curriculum to address the need for increased training to support the pediatrician's involvement in the care for young children with disabilities (Powers & Healy, 1982; Scott et al. 1993).

Ten years after the Task Force report, pediatricians who had completed their residency training in 1978 or later were surveyed regarding their perception of their residency training regarding the areas of pediatrics that were described as underemphasized in the Task Force Report. The results reveled that the residents who received their training during the latter part of the past 10 years since the Task Force, reported significant improvement in the previously underemphasized area of developmental and behavioral pediatrics. There has also been an increase in pediatric sub-specialists in addition to the improved training experience which could lead to the conclusion that the Task Force had a positive impact on residency training in developmental and behavioral pediatrics (Wender, Bijur, & Boyce, 1992). Although improvement in pediatric training has been documented, there are areas that still need improvement.

Over 20 years ago, Powers and Healy (1982) described a national project to provide primary care physicians with continuing education related to children with disabilities. With assistance from OSEP, the AAP recognized the need for continuing education and developed a 16-hour in-service training curriculum. The curriculum had many purposes, one of which was to facilitate physicians' interactions with the educational system. It is not know how many physicians participated in this in-service training.

Numerous surveys were conducted during this time to investigate pediatricians' knowledge of children with disabilities, and determine where further training was needed. In the late 1970s Dworkin, Shonkoff, Leviton, and Levine (1979) conducted a survey that revealed that 79% of the pediatricians described their training about children with disabilities as inadequate. Four years later Powers and Healy (1982) reported the same findings: that 73% of primary care physicians reported they needed further training in the area of children with disabilities. Eight years after this study, another survey of pediatricians was conducted by the New York State American Academy of Pediatrics (AAP) District II, in 1990. Their results parallel that of Dworkin et al., as well as Powers and Healy. Only 15% of pediatricians felt well informed about P.L. 99-457. The majority of the respondents indicated they could see themselves as more involved in the early childhood special education identification process (Cohen, Kanthor, Meyer, & O'Hara, 1990).

Model Demonstration Programs

To help unite the medical and educational systems, many projects have been developed. These projects include in-service training that was developed over 20 years ago (Coury, 1990; Powers & Healy, 1982), community-based developmental sites (Kaplan-Sanoff & Nigro, 1988; Solomon et al., 1994), medical education training models (Garland, Gallagher & Huntington, 1997), and an innovative approach called a birth defects registry (Farrel et al., 2003). All of these programs had one goal in mind: finding and referring eligible children to early intervention as quickly as possible.

A birth defects registry or monitoring program is a surveillance program that is designed to track birth defects and identify children for early intervention. In 2003, there were 33 States that had some type of birth defects monitoring program. Due to this ability to capture important information related to early intervention eligibility, a birth defects registry is a potentially valuable source of information. Almost all surveillance programs maintain a registry of children with diagnosed birth defects in a particular State or geographic region. Thus, birth defects registries can be an efficient way to identify eligible children and provide timely referrals to early intervention. For example, in Maryland, hospitals report the child to the registry and the registry staff contacts the family with information related to early intervention (Farrell et al. 2003).

Because the majority of young children are involved in the health care system in some way, identification and early referral have the greatest likelihood of happening in the doctor's office. The early intervention system needs to recognize this interface as a vital Child Find resource (Blackman, Healy, & Ruppert, 1992). However, many physicians may not have the necessary information and knowledge to make appropriate referrals and therefore may benefit from a collaborative effort.

The Child Development Project at Boston City Hospital consists of a multidisciplinary team of pediatricians, educators, as well as therapists who conduct developmental assessments, facilitate referrals, and provide intervention services for children from birth until age 5. The Project provides these services to the children where they receive their primary care as opposed to a separate clinic (Kaplan-Sanoff & Nigro, 1988).

Another example of a model program to enhance Child Find activities is in Pittsburgh, Pennsylvania. The Allegheny County Department of Welfare in Pennsylvania developed a collaborative model for Child Find activities called community-based developmental assessment (CDA) sites. Each site was located in areas that serve pediatricians and family practioners and also address the educational needs of pediatric residents regarding screening, assessment and referral. Three CDA sites in the Pittsburgh area are used by the project, each utilizing similar screening, assessment, and referral services. At the CDA sites, developmental specialists assess and refer children, if necessary, for early intervention services (Solomon et al, 1994).

Twenty-five years ago, Courey (1990) wrote:

> With appropriate and effective changes in pediatric training at the medical school, residency, and continuing education levels, we can anticipate pediatricians who will have the knowledge, skills and attitude necessary to meet the special health care needs of children with chronic handicapping conditions. Such pediatricians can be expected to participate as case managers or coordinators who are aware of the appropriate community services and resources available to children with special needs (p. 56).

There have been a number of model demonstration projects funded by OSEP related to Part C Child Find activities. For example, University Centers of Excellence in six States were funded to develop innovative approaches to educate the communities on awareness and importance of early identification and early intervention (retrieved from: www.childfindidea.org). This information is useful in understanding what various States are doing regarding Child Find efforts at the local levels.

In Colorado, OSERS awarded a four-year federal research and training grant to the JFK Partners of the University of Colorado Health Sciences Center, Department of Pediatrics, beginning September 1999. The purpose of the project was to increase referrals to early intervention from county child welfare departments. The participants worked with the counties to develop and strengthen relationships between Part C and county child welfare service workers. A guide book was developed and distributed during their local planning meetings. Included in the guidebook is information on legal, medical, and financial resources related to Part C services as well as an overview of Part C and child welfare programs from federal, State, and local perspectives. (retrieved from: www.childfindidea.org/descriptions/colorado_b.htm; www.jfkpartners.org).

Similar to the program in Colorado, a program in Hawaii is also designed to increase referrals to early intervention from other agencies. Hawaii offers the SEEK (Strategies for Effective and Efficient Keiki (child) Find) Project, which is designed to develop, demonstrate, and evaluate methods for improving Child Find that are scientifically based. Project staff members work with professionals in the community who make referrals to early intervention rather than parents or the general public. Gaps and barriers have been identified through quantitative and qualitative needs assessments (retrieved from: www.childfindidea.org/desriptions/seek_b.htm; www.seekhawaii.edu). Shapiro and Derrington (2004) report these efforts resulted in increased access to early intervention by Hawaii's Department of Health and early intervention Child Find efforts. As part of the SEEK project Shapiro and Derrington (2004) conducted research related to aspects of inaccessibility and lack of referral to early intervention from low-income, immigrant, non-English-speaking, military, and homeless families. Their results indicate that access to referral and enrollment across subpopulations varies. Low-income and immigrant families were able to access early intervention more easily compared to children from military families and children without insurance.

Another model demonstration project, The Enhanced Child Find Through Universal Newborn Hearing Screening project in Connecticut is designed to provide support and education related to newborn hearing screening to expecting parents Their efforts have resulted in videotapes and booklets describing the newborn hearing screening process, follow-up hearing testing, and early parent-child communication that is designed for families to review prior to the births of their babies and are disseminated through birthing classes and OB-GYN and midwife offices (retrieved from: www.childfindidea.org/descriptions/hearing_screening_b.htm).

Similar to Colorado's project designed to encourage collaboration between agencies, PEDI-Links, Creating Partnerships between Pediatric Health Care Professionals and Early Interventionists for Child Find is designed to improve

Statewide Child Find efforts in Vermont by enhancing the capability of pediatricians and early intervention personnel to work collaboratively to identify and refer eligible infants and families. This goal is reached by improving efforts to monitor early development and educate primary health care providers and early intervention personnel through a web-based curriculum. The PEDI-Links project has created many products for families, early interventionists, pediatric healthcare practitioners, and obstetrical healthcare practitioners. The products focus on issues related to child development, screening and early identification. PEDI-Links also provides on-line support for families and providers, and strategies for establishing partnerships. All products developed by PEDI-Links are located on their web site and can be printed directly from the site. (retrieved from: www.childfindidea.org/descriptions/peid_links_b.htm; www.uvm.edu/~cdcil/bedilinks/homepageframea.thm).

Promoting Early Identification and Support for Families of Young Children: The Early Connections Project in New Hampshire is designed to create a comprehensive family-centered Child Find system. This project synthesizes a variety of successful approaches to identify young children with disabilities as early as possible. This project began in 1991. The Early Connections Project reports many outcomes. From 1999 to 2001, the number and percent of infants served by Part C early intervention increased in four of six project regions, and increased slightly Statewide. In the same time frame, the number of children aged birth to three served by Part C also increased in four of six project regions due to the work of project teams as well as other factors. The project staff indicates that the increases ranged from 13% to 66%. The number of young children screened for vision and hearing increased through the efforts of various project partners. The project staff also produced and disseminated six educational/public awareness products. They further report a cohort of 130 individuals working diligently with the project to promote Statewide access to hearing and vision screening, parent-completed developmental screening, public awareness and marketing, systemic change, and State and local collaboration. (retrieved from: www.childfindidea.org/descriptions/early_connections_b.htm; http./iod.unh.edu/projects/early_connections.html).

In Montana, the Dynamic Community Connections Project was developed to enhance public awareness and increase referrals to early intervention in the rural areas of Montana. The primary outcome is to demonstrate innovative process for developing Child Find programs that can be replicated in rural communities. The DCCP has also conducted State surveys with both Part C and local coordinators regarding public awareness and Child Find activities. A manual was developed that outlines the steps in building a community collaboration team, to assist agencies in this process. DCCP also provides information on how to plan and facilitate meetings effectively, the basic principles of marketing and developing a public awareness plan, and marketing strategies that agencies can use for their community. To provide further technical assistance DCCP developed a web page that offers additional information to agencies. Included on the website are results of a qualitative survey conducted with several States on effective public awareness strategies at State and local levels. Information about what the participating agencies around Montana are doing in their individual communities is also provided (retrieved from: www.childfindidea.org/descriptions/dynamic_community_b.thm; http://ruralinstitute.umt.edu/dccpchildfind/aboutdccp.thm).

Because there is a limited amount of State-level research in the area of Child Find and public awareness activities, this information on various model-demonstration projects provides useful information. However, these projects are not widespread and only represent minimal Child Find efforts. In addition, there is no research indicating that these projects have lead to an increase in pediatric referrals to early intervention.

Pediatric Training and Education

When a physician finishes the four years of medical school, he/she must complete an additional three years of pediatric residency training. Pediatricians are responsible for learning an immense amount of information, and their program requirements are lengthy. To improve the quality of health care and improve the quality of graduate medical education, the Accreditation Council for Graduate Medical Education (ACGME) was established in 1972. The ACGME evaluates and accredits medical residency programs in the United States (www.acgme.org). The council also sets the guidelines for program requirements for residency education in pediatrics.

Last updated in January 2006, the ACGME has outlined requirements in subspecialty education for pediatricians. Included in subspecialty education is NICU and PICU experiences, and developmental/behavioral pediatric experience. In the Program Requirements for Residency Education in Pediatrics, under the developmental/behavioral pediatrics requirement, it states that the residency program must include instruction to enable the residents to develop appropriate skills in "normal and abnormal child behavior and development, including cognitive, language, motor, social, and emotional components. . . (p.27, retrieved from www.acgme.org)." There is no mention of early intervention or the referral process in the ACGME requirements for pediatricians.

According to the Pediatric Residency Program Director at the University of Maryland Medical System, the reality is, most programs have the one-month block rotation for NICU/PICU and the one-month block rotation for developmental/behavioral pediatrics. The training the pediatric residents receive in early intervention is only incidental by nature of the program locations in the larger cities (personal communication, C. Carraccio, April 14, 2006). Regardless of whether the pediatric residents receive the training incidentally or not, training in early intervention is not an ACGME requirement.

It is important to understand what pediatricians know about early intervention and how they received their training. If we are better able to understand what they know, what they need to know, and how they would like to receive additional information appropriate measures can be taken to accommodate their needs thus increasing appropriate referrals to early intervention. There is some research that documents physicians' training and awareness of early intervention. A number of surveys have been sent to pediatricians containing questions about whether their residency included information on early intervention, their knowledge of the laws and regulations that govern these services, as well as barriers that prohibit them from referring infants to early intervention programs and areas in which they would like continuing education.

According to a survey sent to pediatricians in 2002, doctors identified a number of barriers to early intervention referrals. Almost half of the respondents (46%) indicated a lack of understanding about early intervention's process and procedures, and 45% felt a lack of information about the early intervention program and the availability of services the programs offers are barriers to referrals. Thirty-six percent reported a lack of feedback from the EI program regarding the child's progress as a barrier. A further 30% indicated uncertainty about eligibility criteria and/or a lack of time to deal with the EI program as a barrier. Twenty percent reported a lack of available services and 10% reported a lack of evidence that EI is effective as barriers to referrals. However, most pediatricians (81%) would like to know more about early intervention via written materials (84%) continuing medical education (e.g. grand rounds, conferences) from developmental specialists, as well as in-service training from State level EI providers (56%) (*American Academy of Pediatrics***,** 2003).

For Part C to be effective, it is imperative that pediatricians be aware of and participate in local early intervention systems. Scott, Lingaraju, Kilgo, Kregel, and Lazzari (1993) conducted a survey of pediatricians in Virginia to obtain information related to current screening techniques, referral practices, and training needs. Scott et al. were targeting to what extent the pediatricians were involved in local Child Find efforts. They developed the Pediatricians' Early Intervention Questionnaire to also gain information on Child Find and referral efforts among local pediatricians. The survey consisted of five sections which included background information, methods of developmental screening, referral practices, training needs, and demographic information. The survey was field tested in Maryland by 15 private pediatricians. The modifications were made based on their feedback.

In the larger study, all pediatricians in Virginia were asked to complete the survey, yielding 965 respondents. One hundred fourteen pediatricians were eliminated for reasons such as relocation or no longer serving the early childhood population. This reduced the sample size to 851, with 342 responses, yielding a response rate of 40.18%. The results need to be interpreted with caution because of the limited response rate. Seventy-six percent of the pediatricians indicated that they made a referral when screening results indicated a possible delay. The pediatricians were asked to rank up to three reasons why a referral was not made to the local early intervention program. The top three reasons were that the pediatrician felt the programs were not accessible to the family; the pediatricians were not aware of local programs in their community; and they did not feel that the early intervention program would be beneficial to the infant and family. Over half of the respondents indicated that in their practice, there were no specialists (educational professionals).

The pediatricians were also asked what conditions needed to be present in the child to make a referral. The most frequently referred group (90.6%) was children with a hearing or visual impairment. Infants with chromosomal abnormalities were the second highest ranked group (76.4%). The third highest ranked group was infants with a birth weight of less than 1500 grams (68.9%).

The survey also consisted of questions related to training needs. Scott et al. made a special note that the recommendations for more training were made by graduates in the entire range from 1934 though 1986. The most frequently requested area of training was in developmental screenings and requests for further education on local community resources in early intervention.

Scott et al. indicated that their data reveal that pediatricians are in fact, aware of the need to know of local early intervention resources, as 52% of the respondents requested further education in this area. They concluded that if pediatricians feel that early intervention is beneficial to a certain subgroup of children (children with hearing or visual impairments) they are more likely to refer a child with that type of a disability. Their data suggest that pediatricians recognize a need for further training in developmental/behavioral pediatrics that needs to be part of their medical school training. Also indicated in the data is the significant number of requests for continuing education in the area of early intervention current issues. Developmental screening was the area most frequently requested for information (65.8%). Regional seminars, local workshops, and annual pediatric chapter meetings were the three continuing education programs cited as the most likely to be used.

In interpreting the results of this study, it should be noted that there was a response rate of only 40.18% (342 of the 852 surveys were returned). Further, Scott et al.'s sample only consisted of pediatricians practicing in one State, and there is no mention of any measures that were taken to ensure participant confidentiality. These factors could have a considerable effect on the participants' responses.

Scott et al. acknowledge two other possible limitations. First, the pediatricians who responded to the survey may be those who are more interested in early intervention and therefore may be more knowledgeable about the laws than the pediatricians who did not respond. Second, the study excluded general practitioners. Families living in rural areas of the State may rely more on general practitioners than on pediatricians for well-child visits.

Helm and Shishmanian (1997) provided additional survey findings. They used a qualitative focus group format followed by a survey to local pediatricians practicing in Massachusetts to identify barriers to early intervention referrals as well as training and informational needs of pediatricians. They asked how well pediatricians feel they know early intervention services, and what kind of training they believe they need to be more prepared to play their role in early intervention.

The focus group was composed of three parents who had children in the early intervention system, three early intervention program directors, four State Part C personnel, seven pediatricians, and three representatives from the university affiliated program. The focus group was designed for the participants to discuss barriers that might prevent pediatricians from making referrals in a timely manner and recommendations for pediatric training needs.

The follow-up survey was anonymous, and contained questions related to the respondents' understanding of and comfort with the early intervention system, as well as training they felt would be most helpful based on the focus group. The survey was pretested by both pediatricians and parents, and then mailed to 500 pediatricians who were randomly selected. The researchers reported that 132 surveys were returned, yielding a response rate of 27%. This very low response rate is a significant limitation to the study as was the case with Scott et al. (1993). Low response rate limits the generalizability of the findings, and need to be taken into consideration when interpreting the results.

The focus group identified 22 barriers that obstructed timely referrals by pediatricians to the early intervention system. The top three barriers were a lack of information on the nature of early intervention services, a lack of knowledge of early intervention eligibility criteria, and an uncertainty of the efficacy of early intervention. It is interesting to note that the top three barriers are knowledge-based barriers indicating an insufficient amount of or lack of specific knowledge. These findings are similar to those of Scott et al. (1993) who also reported that a lack of knowledge of early intervention programs, as well as, a lack of awareness of the program effectiveness were reasons why referrals were not made.

The researchers reported that they grouped the participants' responses 'always' and 'usually', and the answers 'sometimes', 'rarely', or 'never' were also grouped. The fact that Helm and Shishmanian grouped their findings is a significant limitation to this study. Even though they justify their reasons for doing this, a response of 'never' is quite different from a response of 'sometimes' and should not be reported as the same. This significantly limits the validity of these findings.

Helm and Shishmanian reported areas of further knowledge-based training included knowledge of early intervention reimbursement system, understanding of the term 'medical necessity', referral based on parental concern, and understanding of early intervention eligibility criteria. An open-ended survey question asking for training needs revealed the following responses: an understanding of early intervention services and eligibility criteria, and understanding of the early intervention financing. The researchers concluded that children and families who are in need of early intervention services may not be referred without pediatricians having adequate and current information.

Helm and Shishmanian used two methods: a focus group and followed by a survey, to identify barriers to early intervention and information on training needs from pediatricians. The focus group consisted of a variety of individuals all with different experiences and expertise in the field of early intervention. However, the significantly low response rate is a major limitation to the study. In addition to the low response rate, the fact that only pediatricians in the State of Massachusetts were surveyed limit the generalizability of their findings. The survey also contained Likert scale responses ranging from 1 (always) to 5 (never). Even though the surveys were anonymous, this type of rating may be considered a limitation.

Pediatricians in Connecticut were also surveyed about their knowledge of and involvement in early intervention by the Connecticut University Health Center. Eight hundred thirteen pediatricians who were currently listed as members of the Connecticut Academy of Pediatrics were mailed a survey that consisted of a checklist of 33 questions. Thirty-six surveys were returned because the respondent was no longer practicing pediatrics. Of the 777 surveys, 311 were returned, yielding a response rate of 42.9%. This response rate is significantly low as was the case with the two previous surveys.

The survey contained questions related to the pediatricians' background (i.e., medical school and residency training), characteristics (i.e., when the respondent graduated from medical school, and completed the residency requirements), as well as their training related to children with disabilities, and their knowledge of the current legislation (Part H, of P.L. 99-457). The survey was authorized by numerous professionals including the Director of the Division of Child and Family Studies and the Director of the Children with Special Health Care Needs at Newington Children's Hospital (*Survey of Connecticut Pediatricians*, 1997). However, it should be noted that no information is provided on where the survey questions came from, and whether the survey was pilot tested. There is also no mention of participant confidentiality which could be a significant factor in the participants' responses.

The results revealed that the average respondent graduated in 1972, and completed residency in 1976. The survey showed that the 24.5% of the respondents received training on children with disabilities in medical school, and 56% reported they received training during their pediatric residency. Only 23.5% of the respondents indicated that they had heard of Part H, while 72% reported they had not heard of Part H. Of those who reported knowing of Part H, only 43% considered themselves 'somewhat informed', and 17.8% described themselves as 'well informed'.

When asked about their interest in training on children with disabilities, 79.7% were interested. Those who reported they were interested were then asked to rank the format choices in the order of their most preferred to least preferred method. Results reveal that brochures were the most preferred training format, with the second most preferred format being grand rounds. "Mini fellowship/post graduate work" was the least preferred method.

The researchers concluded that most pediatricians are not informed about legislation pertaining to young children with disabilities (Part H, at the time this paper was published). The respondents also reported a lack of training related to children with disabilities in both their medical school and residency training programs. The researchers indicated that their most significant findings were the large number of pediatricians who were interested in learning more about young children with disabilities. Their results support the need for increased information and training to improve pediatricians' abilities to understand and refer young children to the early intervention program. This study further supports the fact that few States have successfully integrated the health system into the early intervention system.

As with the two previous studies, significant limitations must be noted when interpreting the findings of this research. The first being the low response rate of 42.9%. It is reported that nearly 80% of the respondents were interested in receiving training in early intervention. However, a yes/no question asking pediatricians if they would like to receive additional training is a leading question, especially if the participants' responses are not being kept confidential. This high percentage could, in fact be misleading. Another limitation to this study is the fact that the survey was not pilot tested and the researchers did not use an already developed questionnaire.

The findings, however, are quite similar to those of Helm and Shishmanian and Scott et al. Pediatricians are not entirely aware of early intervention or the laws that govern its programming. They also do not see the efficacy of early intervention and don't understand the process for making referrals.

Professional policies and literature have advised physicians take a more active role in early intervention. However, many barriers exist that impede their full participation. Buck, Cox, Shannon, and Hash (2001) conducted a survey of both local Part C coordinators as well as physicians in Virginia about physician knowledge, referral practices, and their communication preferences with the local early intervention system.

Buck et al. used two separate surveys – one with pediatricians and family physicians; the other with coordinators of the 40 Local Interagency Coordinating Councils (LICC) in Virginia. They were attempting to identify the need as well as the desire for training and information related to early intervention, and the respondents' most preferred method for receiving the requested training or information. Their response rate was only 32.6% with pediatricians representing 61.9% of the respondents and family physicians representing 38.1%.

Buck et al. found that over 65% of the physicians received information related to early intervention, and 75% felt they were knowledgeable about early intervention in their community. Fifty-nine percent indicated no interest in formal early intervention training. Fifty percent indicated an interest in formal training for their office staff (i.e., nurses). Physicians responded that they prefer to receive early intervention information in reports (65%) or formal letters (56%). Only 13% preferred to receive information through an office visit or phone call.

The second survey was mailed to the 40 LICC coordinators to determine their perceptions of physician referral practices, and strategies used to educate physicians at the local level about early intervention. Thirty-three surveys were returned, with a response rate of 83%. Thirty-two surveys were complete, and used in the data analysis. An overwhelming majority of respondents (97%) indicated they had provided early intervention information to local physicians. Sixty-six of the coordinators believed that formal training for physicians would be most beneficial and would improve communication. However 50% of the respondents reported very low physician referral rates and 60% indicated that physicians rarely or never referred children to the central point of entry into the early intervention system. Ninety-seven percent of the council coordinators desired more referrals from physicians and wanted to increase physician involvement on their councils.

Buck et al. identified five themes from their findings. The first theme was that physicians' need for information and the local coordinating councils' strategies for sharing early intervention information may not be consistent. Local council coordinators ranked several strategies as 'successful' when responses from the physicians indicated that the same strategies were not listed as priorities for receiving early intervention information. For example, they found that physicians were not interested in formal training. This is consistent with the findings of the *Survey of Connecticut* Pediatricians who reported the least preferred method of receiving information was through multidisciplinary and mini-workshops. However the council coordinators' believed that formal training for physicians would improve communication and referral practices.

Physicians clearly prefer written communication in the form of formal reports or letters; whereas council coordinators identified phone calls and office visits as their preferred methods of communication. These findings again parallel those from the *Survey of Connecticut Pediatricians* who also reported pediatricians preferred receiving information through brochures and newsletters.

Buck et al. explain many challenges physicians face in their role in the early intervention system. Physicians must first recognize that the early intervention team model is different from that typically experienced by physicians in hospital or other medical center settings. Difficulties are often encountered because of a lack of common terminology, different levels of training and knowledge, and different expectations for the outcomes. Further barriers include a limited amount of time, and a lack of financial compensation.

Buck et al. provide current information related to physicians' knowledge and preferred methods of receiving information about early intervention. However, there are limitations to the study. First, as indicated earlier, a response rate of 32.6% is low and limits the generalizability of the findings as was the case with the previous pediatric surveys. Second, no information was provided about the survey – where the questions came from and whether it was pilot tested. With no information on this topic, the findings may not be valid.

In addition to surveys documenting pediatricians' awareness of early intervention, there was a single survey documenting what the States are doing to promote pediatric awareness of early intervention. Berman and Melner (1992) surveyed the Part C (Part H, at the time of the study) State lead agencies as well as

Early Education Programs for Children with Disabilities (EEPCD) projects. They compiled a survey with questions related to communication with primary referral sources. The survey consisted of 11 questions on description of practices, evaluation methods and products. There is no information provided on a pilot testing of the survey.

The survey was mailed to the EEPCD projects and institutes as well as the State Part C (Part H at the time of this study) lead agencies. The researchers reported synthesizing 30 written responses. There is no further information provided on how many EEPCD projects and institutes were surveyed or how many responded. It was not clear how many of the 30 respondents were Part C lead agency coordinators.

The results of the survey were categorized into themes including communication from early intervention to medical primary referral sources. A second theme: what doesn't work in communicating to primary referral sources was also developed. The researchers also categorized responses into a third theme evaluating outcomes. Berman and Melner reported a basic and important consideration about communicating to physicians. They emphasized that early intervention personnel must recognize that the health care system existed long before early intervention and is structured quite differently. They further indicated that expecting medical primary referral sources to fit into early intervention will not work because it is not a 'natural match'. This is a surprising statement and one that does not foster a collaborative and respectful relationship between the educational and medical community.

Berman and Melner reported that an effective link to communication between early intervention programs and physicians is through nurses and other maternal and child care personnel. They further reported the need for continuous and ongoing communication between agencies and not simple sporadic contact. Many States reported sending packages of brochures and information on referral procedures to physicians. Newsletters were also used by a few States. One EEPCD project emphasized that in addition to physicians, it is important to build relationships with other personnel who have regular contact with families including discharge planners, child life specialists, nurses and therapists.

One State reported that simply disseminating brochures and handouts is not enough. Systematic follow-up, sharing of information and trust building from all parties involved is necessary. Eight States reported training projects that were used to educate physicians and other health care personnel on the benefits and importance of early intervention and how to make appropriate referrals to local programs.

The researchers further reported many efforts to communicate to primary referral sources that are not effective. Singular approaches are not effective. Rather, a combination of approaches including presentations at conferences, newsletters, and participation in grand rounds is more likely to result in consistent referrals. Expecting physicians to attend multidisciplinary workshops has also not been effective according to one State. This finding is consistent with that of Buck et al., and the *Survey of Connecticut Pediatricians* who also found that pediatricians are not interested in workshop type activities.

Berman and Melner also mentioned that many States had little to report with regard to how they are determining whether information has reached primary referral sources. It appears that the States are not evaluating the effectiveness of their efforts to educate the medical community about early intervention, according to this study.

Berman and Melner provided useful information related to reaching medical primary referral sources that was not found elsewhere. However, the report is 13 years old and there is no information provided on who responded to the survey (EEPCD personnel and Part H lead agency coordinators), and there is no response rate provided. Further, their methods for data analysis and a review of the data received are not provided.

Summary

I reviewed five studies in this section. Three studies were surveys investigating pediatricians' awareness of early intervention (Helm & Shishmanian, Scott et al., *Survey of Connecticut Pediatricians*). Each survey had a very low response rate which significantly limits the generalizability of the findings. Another factor that limits the generalizability of the findings is that each study was conducted in only one State and all those States were in the northeast. The remaining two studies also used surveys to investigate pediatricians' and LICC coordinators (Buck et al.), and Part C coordinators and EEPCD project directors (Berman & Melner).

The findings of the five studies are similar in many ways. Pediatricians are not entirely aware of early intervention legislation, programming, eligibility, and the referral process. Pediatricians are aware of their need for continuing education and prefer brochures and news letters with workshops and formal training as the least preferred method (Buck et al., *Survey of Connecticut Pediatricians*). However Scott et al., found pediatricians also find seminars and annual pediatric chapter meetings dedicated to early intervention as preferred methods of receiving current information. It is interesting to note that Buck et al., who surveyed both pediatricians and LICC coordinators, found a significant difference in preferred methods of communication. The LICC coordinators thought formal training was most beneficial and pediatricians thought it was least beneficial. Berman and Melner reported that a combination of methods including grand round presentations, newsletters, and brochures is most beneficial. They also reported the need for continuous and ongoing communication with the medical community.

NEILS Research

Close to twenty years ago, federal legislation (P.L. 99-457) created early intervention programs for infants and toddlers. OSEP commissioned SRI to provide information about Part C and its participants. In 1996, the National Early Intervention Longitudinal Study (NEILS) began. NEILS findings are based on a nationally representative sample of children and families who receive early intervention services under Part C. These participants were recruited as they entered early intervention from September 1997 through November 1998 (Spiker et al., 2004). The conceptual model behind NEILS is based on the recognition that the outcomes experienced by children and families in early intervention are influenced by many factors including parent, child, and community factors (Scarborough et al., 2004). This is consistent with the transactional model used in this research. (See Figure 1). Not only do many factors influence a child's development, the individual interactions between the factors influences development as well. These interactions extend from the family to the pediatrician, to the Child Find efforts, and on to the State Part C lead agency.

Using the NEILS data, Bailey et al. (2004) investigated families' initial experiences with early intervention. Families were questioned about their perceptions of their interactions with the medical community. Bailey et al. conducted 2974 telephone interviews completed within 16 weeks of enrollment in early intervention. Results indicated that on average, first concerns were expressed by the family at 7.4 months of age; first diagnosis was given at 8.8 months; early intervention was sought at 11.9 months; referral occurred to early intervention at 14 months; and the IFSP was completed by 15.7 months of age. It appears there is a problem in the length of time from diagnosis to referral to early intervention, with an average of 5.2 months. Research can assist in identifying possible barriers as well as why the referral process takes so long.

Among the families who initially became concerned about their child's development after the first month of life, 86% reported discussing their concerns with a doctor or other medical professional first. The researchers indicated that their findings justify the need for the medical community to be aware of early intervention in order to talk with the family on their options (Bailey et al., 2004).

Scarborough et al. (2004) also used the NEILS data. They presented national estimates of characteristics of infants and toddlers as they entered early intervention. Scarborough et al. sampled 3,338 infants and toddlers drawn from the NEILS database of over 170,000 children. Their findings are based on a 40-minute telephone interview with the parent or primary caregiver. Their results revealed that of all the infants and toddlers who entered early intervention 22% qualified because of a diagnosed medical condition. Thirty-eight percent entered the program before their first birthday. The second most frequent reason for early intervention eligibility was pre- and perinatal abnormalities for 20% of the children.

When investigating the health status of the infants, those enrolled in early intervention were eight times more likely to be rated as having either fair or poor health compared to children in the general population. The researchers also report that a disproportionate number of infants in toddlers in early intervention had low birth weights. Nearly one third (32%) were born at low birth weights, which is four times the rate in the general population.

Keeping in mind that there is variation in State eligibility criteria, as well as eligibility criteria differences in Part C and Section 619, Wolery and Bailey (2002) suggest it is important to enhance the role of the pediatrician and other health care providers in the early identification process. They further indicate that "of special focus should be an examination of the mandated Child Find components of IDEA to compare and contrast the efficacy and implementation of various Child Find models" (2002, pp. 90-91).

In 2002, an estimated one out of every eight babies in the US was born preterm. Since 1992, the rate of preterm birth has increased by 13% (www.marchofdimes.com/peristats). The earlier a baby is born, the greater the likelihood of significant medical complications. In other words, as birth weight decreases the prevalence of medical complications increase. For example, the

University of Maryland Medical Center in Baltimore, Maryland has what is called a level III NICU. In 2004, there were 484 infant admissions. Of these infants 10 (2%) had a grade III intraventricular hemorrhage (IVH) and 5 (1%) had a grade IV IVH. One hundred and eleven infants (22%) had a birth weight of less than 1200grams. Seventy (14%) had BPD. All of these infants, by virtue of their diagnosis, automatically qualified for the infants and toddlers program under conditions of established risk in the State of Maryland.

Infants who have left the NICU with a medical diagnosis that falls under the high probability category should already be enrolled and referred to the early intervention program, possibly before they are discharged from the hospital. For this reason, the neonatolotist and NICU personnel should have current information on early intervention in order to educate parents of their rights, options and services their infants is entitled to receive.

Conclusions

It is evident from the extant research that regardless of whether pediatricians received training in early intervention during their residency programs, States must provide continuing education to these primary referral sources. Although there is no mention in the ACGME program requirements for pediatric residents, there is a small section related to intervention in the American Board of Pediatrics (ABP) Subspecialty Certifying Examination Content Outline for neonatal-perinatal medicine. The outline is broken down into medical diagnoses. Under the diagnosis of cerebral palsy, the neonatologist is required to know the various interventions that are available for children with cerebral palsy, including physical and occupational therapy. Under the mental retardation diagnosis, the neonatologist is required to know the efficacy of various programs designed to improve cognitive outcome. However, under a section titled Neurodevelopmental Intervention Strategies, the neonatologist is required to understand the rationale behind early intervention and determine what services make up early intervention and when they are indicated. Further, the neonatologist must "know the limitations of early intervention services" (p. 51). This is an interesting statement made by the ABP, and there is no further information provided.

A significant number of children receiving early intervention have spent time in an NICU. For this reason, NICU staff should receive current and continued training in early intervention as now mandated in IDEA. Due to the increasing number of babies who are being born preterm and subsequently spending time in the NICU it is important to understand if the States are educating the NICU staff on the importance of early intervention and how to make referrals to local programs. At this time, this information is important to know because of the new component in the IDEA amendments. In addition to the general medical community, States must specifically target their public awareness efforts to personnel who work with premature infants and their families.

There is currently no research documenting what the States are doing to promote early intervention to the medical community and how they are evaluating the effectiveness of their efforts. Based on the findings of research reported in this review, most pediatricians are not aware of early intervention and do not know how to make the necessary referrals. Moreover, there is a discrepancy between how the pediatricians prefer to receive information and what is being done at the local level to disseminate information on early intervention. According to Annual Reports to Congress, States are not doing an effective job of promoting early intervention to the medical community.

This study is designed to investigate what the States and US territories are doing to educate the medical community and how they are evaluating the effectiveness of their efforts. The study also is designed to determine if any barriers exist that prohibit or limit efforts to reach out and educate the medical community.

Chapter 3: Methodology

In this chapter I describe the participants, instrumentation, and data collection methods used to address the research questions. This study is designed to investigate what the States and US territories are doing to promote early intervention to medical community. Of special interest in this study are the medical personnel who work with families and infants in the NICU. I address the following research questions:

1. What are the Part C lead agencies doing to promote Child Find and early intervention to the medical community in general, and more specifically NICU personnel?
2. How are Part C lead agencies evaluating the effectiveness of these public awareness campaigns?
3. What are the current barriers to promoting early intervention to the medical community?

Study Overview

Consistent with the transactional focus, data collection consisted of three methods to address pertinent interactions related to early intervention services within a child's environment. Each method focuses on a different factor that could potentially influence a child's access to early intervention. The first method of data collection was a review and analysis of each State's policy as it pertains to Child Find and public awareness to the medical community. The State policy analysis is a more distal variable in the transactional framework. The second method of data collection was an analysis of public awareness plans related to efforts to inform the medical community about early intervention services. This variable is influential in child development because it directly relates to efforts to reach out to the medical community in a more focused manner than the general State policies. Both the policy and plan analysis are discussed together.

The third method of data collection was a questionnaire sent to each State and territory's Part C lead agency coordinator. The questionnaire consisted of inquiries into the State-level collaboration efforts with the medical community; the referral and data collection systems of each State; and what barriers are experienced in the promotion of Child Find to the medical community. It is important to understand what the States are doing to promote early intervention and what difficulties they are experiencing in order to better develop a more collaborative and comprehensive approach to Child Find, early intervention, and child development.

Design

In this study I used descriptive research. The goal of descriptive research is to collect data in order to answer questions related to the current status of issues or topics (Gay & Airasian, 2003). The study was not designed to test hypotheses, explain relationships, or make predictions regarding the State and territory public awareness efforts to promote early intervention to the medical community. Rather, the study was designed to collect detailed, factual information on what the States and territories are doing to educate the medical community through their policies, plans, and practices. The study was also designed to identify any problems the States and territories may be experiencing in this process. Lastly, the study was designed to evaluate the State and territory public awareness efforts toward the medical community (Isaac & Michael, 1997). Program efficacy depends on its sound implementation. A potentially effective public awareness model cannot be expected to demonstrate positive effects if it is not delivered and monitored appropriately, or if the intended recipients (i.e., the medical community) are not fully participating (Meisels & Shonkoff, 2000). Therefore, program evaluation is paramount to program effectiveness and a significant component of this study.

Data Collection Procedures

Data were collected using three methods. First, each State's policy pertaining to Child Find and public awareness efforts as they relate to the medical community was obtained and analyzed. Second, efforts were made to obtain each State's public awareness plan. Public awareness plans were received and they were analyzed using the same format as the policy analysis. Third, a web-based questionnaire was sent to each of the 51 Part C lead agency coordinators in the United States, as well as 5 United States territory coordinators.

Policy and Plan Analysis

For the policy analysis, and plan review I used a conceptual model for the analysis of policy implementation from Sabatier and Mazmanian (1981), and Caron (2003). They emphasize the linkage between the actual behavior (e.g., Child Find efforts) and the political, economic, and legal context in which the behavior occurs, as well as the ability of the statute to outline the implementation process.

Pressman and Wildavsky (1984) indicate that many policies are based on sound ideas, but they encounter significant difficulties in practical application. Therefore, a policy's value must be measured in terms of its appeal in addition to its implementability. Only by evaluating the intended and the actual consequences can you determine whether a policy has been well or poorly implemented. Therefore, evaluation includes the analysis of the implementation. Since many objectives that can be monitored and evaluated are often omitted from policy designs; evaluation therefore becomes policy analysis.

Using a combination of Sabatier and Mazmanian's (1981) conceptual model and Pressman and Wildavsky's (1984) method of policy analysis, I evaluated the State and territories policies and public awareness plans on the outlined Child Find efforts as well as the clarity of the implementation process. This conceptual model and method of policy analysis contribute to the ecological framework of this study.

Each policy and plan was reviewed based on a number of variables: (1) Are there clearly stated short term objectives? This question addresses the wording of the objective and whether it is clear or unambiguous and vague. Without a clearly worded objective, implementation, and subsequent evaluation are difficult to achieve. (2) What types of public awareness materials/efforts are done? This question addresses the efficiency of their selected processes. Each policy and plan was evaluated on whether or not their Child Find program has a variety of different methods to educate the medical community on early intervention. (3) To whom is the information disseminated? This question specifically details who is intended to receive the public awareness information on early intervention. For example, are the States including medical students, nurses, residents, and therapists? (4) When will the information be disseminated? This question addresses the timelines set forth by the States and territories related to when the material is provided to the medical primary referral sources. It is essential to have a timeline for implementation in order to evaluate the effectiveness of the efforts. (5) How are States and territories evaluating the effectiveness of their efforts? This final question seeks to answer whether and how the States and territories are evaluating their public awareness efforts to the medical community.

I analyzed these specific components of the State and territory policies related to Child Find/public awareness efforts to the medical community based on Sabatier and Mazmanian's (1981) and Pressman and Wildavsky's (1984) methods of policy analysis. I developed a rubric to analyze the State and territory policies and the public awareness plans, using Caron's (2003) framework for policy analysis. (See Appendix B). The coding scores were as follows: (0) is recorded if there is no mention of the variable, (1) is recorded if the variable is mentioned vaguely or ambiguously, (1.5) is recorded if the variable is mentioned vaguely or ambiguously, but there is mention of the medical community, (2) is recorded if the variable is clear and concise, and (2.5) is recorded if the variable is clear and concise, and there is mention of the medical community.

Each State policy was obtained from the Regional Resource Federal Center (RRFC) Network (obtained from www.dssc.org/frc/rrfc.htm). The RRFC is comprised of six Regional Resource Centers for Special Education in addition to the FRC (Federal Resource Center for Special Education). The six Regional Resource Centers (RRC) assist State education agencies in the systemic improvement of policies related to children with disabilities. Each State is served by a RCC.

After each State policy was obtained, a second coder was trained in the coding schema. (See Appendix B for the scoring protocol.) The second coder was a doctoral student in early childhood special education and has experience in State policies related to special education. Five States (10%) were randomly chosen for inter-rater reliability training. After the coding schema was explained to the second coder, each of the five State policies was coded simultaneously, by both coders. By the third State policy, both coders were achieving the same scores for each State policy analysis.

After thoroughly discussing the State policy coding schema, 13 States (26%) were randomly chosen to calculate inter-rater reliability. Three State policies were replaced by another three State polices that were also randomly chosen, because the original three did not mention any public awareness activities. Each coder independently scored each State policy using the scoring rubric. The coders met after completing the 13 State policies to discuss the findings.

Of the thirteen States, five States (38%) were coded and scored exactly the same by both coders. The remaining eight State policies were discussed until 100% consensus was reached on how to code the policies. (See Appendix D for inter-rater reliability coding scores.) Based on the inter-rater reliability, I made six additions to the coding schema. For the second variable, we concluded that screening efforts were not going to be counted as types of public awareness efforts or materials. We scored a "1" for variable three if the words 'general public' were mentioned as to whom the information would be disseminated. Two additions were made to variable four. First, we scored a "1" if the only mention of a timeline was the word "annual", however, if an actual date was provided (for example, 'by November 1st') we gave that variable a "2". The fifth and final variable also had two additions. If there was mention of a person who is accountable for Child Find activities, we scored a “1” for that State. We decided to not count any mention on data evaluation for discrimination or disproportionate representation of minority students as short-term objective evaluation. After discussing the changes to the scoring rubric, each coder scored the 13 State policies again until consensus was reached. Since I used the same rubric and scoring format for both analyses, inter-rater reliability was not repeated for the public awareness plan analysis.

Survey

Each State and US territory has designated a lead agency to monitor and implement Part C early intervention programs. The lead agency is designated by the governor of each State and is responsible for the administration and supervision of Part C early intervention programs. The lead agency is further responsible for enforcing any obligations under Part C and provides any necessary technical assistance to carry out these requirements. Through program monitoring, the lead agency is responsible for correcting any program deficiencies (C.F.R. 303.500; C.F.R. 303.501).

Each lead agency has a coordinator who oversees this process. The participants in this research were the Part C lead agency coordinator in each State and US territory. I chose these participants because this research is being conducted on a national level and information on a State-level basis is being sought. The lead agency coordinator has direct knowledge of and access to any public awareness programs that are carried out in the State.

Pilot testing. Before the State coordinators were surveyed, the questionnaire was pilot tested in order to determine if the questions were worded appropriately and if there was any additional information to ask. Pilot testing is a recommended practice to help clarify ambiguous items and eliminate redundant items. Pilot testing also provides useful information about any deficiencies and allows the opportunity for questionnaire improvement (Converse & Presser, 1986; Dillman, 2000; Gay & Airasian, 2003; Isaac & Michael, 1997). Further, Dillman and Bowker (2001) recommend pilot testing the questionnaire to help minimize measurement error that results from inaccurate responses stemming from poorly-worded questions.

Dillman (2000) recommends four stages in the pre-testing process of questionnaires. The first stage is a review by knowledgeable colleagues and analysts. The purpose of this stage of pre-testing is to elicit suggestions from the individuals based on their experience with previous surveys as well as knowledge of study objectives. These are people who can identify with respondents and determine how likely it is that each question can or will be answered.

In addition to a State Part C coordinator, each local jurisdiction in each State has designated someone to oversee the local implementation of Part C programming. For example, in the State of Maryland every county has a local Part C coordinator. The participants in the pilot testing of this survey were the local Part C coordinators in each county in the State of Maryland. These participants were chosen because of their knowledge of the local implementation of Part C, and so as not to eliminate any State from participating in the full survey.

Fourteen local coordinators received an initial phone call explaining the nature and intent of the research. Five coordinators agreed to participate. I then mailed the questionnaire to them along with the consent form. I encouraged each participant in the pilot testing to make comments and suggestions regarding the questionnaire's directions, recording procedures, and specific items. To improve the content validity, I also asked the participants to comment on the completeness of the questionnaire and whether further items should be added.

I provided a self-addressed stamped envelope for the participants to return both the survey and consent form. I report the changes that were made based on the feedback from the pilot testing under *Changes to the Questionnaire*.

This first stage in the pretest process also involves consulting people who have analyzed similar data and know that certain responses to a particular question may not be used due to a lack of variation in the response categories. For this reason, three people at OSEP were asked to review the questionnaire. Two individuals agreed to look over the questionnaire. One individual has conducted similar research in the area of web-based surveys to State-level Part C coordinators. The second individual is an expert in the area of early intervention policy. In addition to the experts from OSEP, two experts in the area of survey research were asked to review the questionnaire. One survey expert responded, and reviewed the questionnaire providing useful information related to the questionnaire design and wording. I discuss the changes that were made based on this feedback in *Changes to the Questionnaire.*

Dillman's (2000) second stage in the pre-testing process involves interviews to evaluate cognitive and motivational qualities of the questionnaire. This process is called a cognitive interview. The cognitive interview method involves reading the questions to the respondent. The respondent is asked to report aloud everything that they are thinking as they attempt to answer the questions (Fowler, 1995; Tourangeau, Rips & Rasinski, 2000). Their responses are then written down and analyzed for evidence of misunderstanding and other questionnaire difficulties. One local coordinator participated in a cognitive interview. Dillman explains the purpose of this stage is to make sure the words are understood and that the questions are interpreted by the respondents as intended.

This second stage in the pre-testing was by far the most useful. It was very beneficial hearing what the coordinator was thinking when reading the questionnaire, especially in terms of the wording of the questions. Many valuable suggestions resulted from the cognitive interview, and are discussed in the next section.

The third and fourth stages in Dillman's pre-testing involve another small pilot study and a final check of the questionnaire. This occurred at the end of the pilot and pre-testing stages. The purpose of this stage was to have a few participants complete the questionnaire in the web-based format to determine if there were any areas that needed to be perfected. This stage occurred when the web-based survey was complete and ready to be sent to the State-level coordinators.

Changes to the questionnaire. Many changes were made to both the questionnaire and the cover letter that resulted from the pre-testing process. One individual at OSEP suggested that I give the coordinators the opportunity to respond using other methods in addition to the web-based format. Based on this suggestion, I added to the cover letter, that if the coordinator preferred, the questionnaire could be mailed or completed over the phone. Almost all of the pre-testing participants suggested giving the questionnaire both a title, and directions for completion.

Many participants also suggested that monitoring efforts be added as a response category in the question in which the respondents are asked about their collaboration efforts with the local coordinators. Under the section of the questionnaire related to referrals, many participants indicated that they all collect referral data in a different way, and categorize where the referrals come from differently. For example, one county mentioned they group all the referrals from pediatricians, hospitals, and health clinics into one category of medical referrals. Based on this feedback, I added a question in which the respondents were asked to type in a text box, where their State collects referrals from, and how many referrals they received for the 2004 fiscal year.

I eliminated one question from the questionnaire because most respondents did not understand the question, or did not have the information available. That was the question that asked respondents to provide the numbers of the levels II, III, and III or IV NICUs in their State. The information that would have been provided from this question would have given a general idea of how familiar the coordinators are with the NICUs in their State, and provided information related to the size and population of the State. However, this information was made available through other inquiries in the questionnaire, related to the number of referrals and whether the State collects data on referrals from the medical community.

Informed Consent

In this research there were two consent forms; one for the local coordinators participating in the pilot testing of the questionnaire (See Appendix D), and another for the State-level coordinators participating in the web-based survey (See Appendix E). Both groups of participants were given a consent form explaining the nature and intent of the study. For the local coordinators the consent form was mailed along with the questionnaire. For the participants completing the web-based survey their consent to participate was assumed when they completed the questionnaire.

Questionnaire. The questionnaire consisted of 30 questions. (See Appendix F for the questionnaire in web-based format.) To improve its usability, each question is short and to the point (Converse & Presser, 1986; Isaac & Michael, 1997). Of the 30 questions, 19 are closed questions in that the participant must choose from response categories provided. Forcing participants to choose among offered alternatives as opposed to answering the question in their own words is a widespread criticism of closed questions. However, closed questions provide the response options and therefore are more specific and more apt to provide the same frame of reference to all respondents as opposed to open questions. A carefully pretested closed form is preferred due to its greater specificity (Converse & Presser, 1986).

Of the 19 closed questions, 15 were yes/no questions. There were five open-ended questions in the questionnaire where I asked the participant to answer the question in their own words. These questions were left open-ended because not enough is known to provide response categories (Converse & Presser, 1986). In five questions I asked the respondent to provide a numerical answer. Response categories were not provided. The questionnaire concluded with an open-ended question in which I asked participants to provide any technical assistance they would require in carrying out their Child Find and public awareness efforts to the medical community. The questions were rooted in the literature documenting pediatricians' awareness of early intervention, information they would like to know, and how they would like to receive the information. Questions were also rooted in what is required by the federal law as far as Child Find and public awareness requirements.

The questions were organized into six categories. The first category included questions related to background and demographic information. The State coordinator was asked to provide information related to how many staff members are responsible for public awareness activities. Also included in this section are questions on the State's and US territory's automatic eligibility categories (i.e., high probability conditions; conditions of established risk) for early intervention.

The second set of questions was related to the State ICC. The questions query the participants on the ICC as well as collaboration efforts with the medical community. There were also questions on the State's public awareness plan and how the Part C coordinator monitors the plan's effectiveness. I felt it was necessary to collect data on who serves on the State ICC boards to better understand the extent of collaboration between the educational and medical communities.

The third set of questions was based on the State's referral process and how the Part C coordinator monitors referral sources. The questions in this category related to whether data is collected on the number of referrals received, as well as if these data are used to adjust public awareness plans. States are not required to report referral sources to OSEP (i.e., parents, hospitals). However, some States and territories collect these data. For those States and territories that do, these data may be useful to consider when determining the effectiveness of their public awareness efforts targeting certain populations.

Information related to public awareness campaigns were the focus of the questions in the fourth section of the questionnaire. One of the goals of Child Find is to promote referrals to early intervention. This is accomplished by developing and implementing practices to reach as many primary referral sources as possible (Dunst, Trivette, Appl & Bagnato, 2004). It is stipulated in IDEA that Child Find be conducted in part by developing and implementing a public awareness program or campaign (*Early Intervention Program,* 2002). Questions in this section were related to the State plan on promoting early intervention and the methods States use to contact primary referral sources.

The fifth section included questions directly related to the coordinator's knowledge of the medical community. The coordinators were asked how they ensure the staff in the States' NICUs are educating parents on their options in the early intervention programs in the State.

The final section of the questionnaire included inquiries on whether the State or territory has a birth defects registry and if the coordinator has experienced any barriers to promoting early intervention to the medical community. The questionnaire concluded with an open-ended question in which the coordinators were asked if there is any information that would be beneficial in their attempts to promote early intervention to the medical community.

Social exchange theory and response rate

I designed multiple measures to maximize the response rate. In addition to the short number of questions and the fact that the majority were closed questions, I used a web-based method to increase response rate as well. However, research is conflicting about whether there is an increased response rate for electronic over postal surveys (Dillman, 2000; Schonlau, Fricker & Elliot, 2002). An advantage of web-based surveys is a potential decrease in delivery and response time and cost. Participants were also provided with the opportunity to complete the questionnaire via phone call or mail if he/she preferred.

The web-based survey design was chosen over mailed questionnaires for numerous reasons. Schonlau, Fricker, and Elliott (2002) recommend using an internet survey when the survey can be conducted in an organization that has a current list of email addresses for the intended population. The National Early Childhood Technical Assistance Center (NECTAC) keeps a current and updated list of all the State and territory Part C coordinators.

In addition, the web-based survey method allows for automatic and instantaneous responses which can be recorded into the database via online entry. Similar to Dillman et al., Schonlau et al. explain that the benefits in terms of cost and timeliness are greatest when you can contact the target population initially by e-mail. These plusses make the internet method a logical choice.

The participants in the survey research component were the Part C lead agency coordinators in each State and US territory. An initial letter explaining the purpose and intent of the research was mailed to each coordinator. (See Appendix G for the initial letter.) In the letter, I included a date that the participants would receive an email with a link to the web-based survey. Dillman et al. (2001) recommend using a dual-mode strategy for contacting participants – using mail and/or email for prenotification of the questionnaire.

Social exchange theory, a theory of human behavior, was used as the theoretical foundation for the survey component of data collection. Social exchange theory maintains that an individual's actions are influenced by the return that these actions are expected to bring from others. Three elements: rewards, costs, and trust, are significant for predicting a particular action (Dillman, 2000).

Rewards are what the individual can expect to gain from a particular activity. For the purposes of this research, the reward is what the Part C coordinator can expect to gain from completing the survey. There was no tangible reward being provided, however Thibault and Kelley (1959) explain that showing positive regard and being regarded positively are a way to provide rewards. Showing respect to the Part C coordinator by providing a contact number if they have questions, personally addressing all correspondence and providing a reason why the survey is being done were small, but not inconsequential ways I showed positive regard to the coordinators (Dillman, 2000).

Costs can be explained as what the individual gives up or spends to obtain the reward. In this research, the costs for the Part C coordinators were the time it took to complete the questionnaire. Dillman (2000) suggests making the questionnaire as short and easy to complete as possible and avoiding as much inconvenience to the respondent as possible. Based on these suggestions, the questionnaire was pilot tested to improve ease of completion and enhance user friendliness. As indicated earlier, there were only 30 questions. Of those 30 questions, 18 were yes/no or multiple choice.

In attempt to avoid inconvenience for the coordinator, and to make the process of completing the questionnaire as easy as possible, I used a web-based format. The respondent needed to only click on the appropriate response or type in the answer in the text boxes. To return the questionnaire, the respondent needed to only click on the button titled “submit”.

In addition to the web-based format, some questionnaires were also mailed to the coordinators. To minimize inconvenience in this format, I provided a self-addressed stamped envelope to return the questionnaire. Just as costs and rewards are associated with the respondents’ decision to respond to the questionnaire, they can also be associated with the coordinator not responding. Sometimes people may respond to a questionnaire simply because they are concerned that by not responding, they will receive additional reminders (emails and phone calls in this case) which they may wish to avoid (Dillman, 2000).

The third element, trust, can be explained as the expectation that the rewards of doing something will ultimately outweigh the costs, in the long run. Under these conditions of social exchange, it was important to assure the coordinators that what was promised (helping us understand public awareness efforts) would, in fact, happen. However, Dillman (2000) suggests that making the questionnaire appear important and reminding the respondents of a university-based affiliation could increase trust between the coordinator and the researcher. I implemented both of these suggestions by using University of Maryland letterhead and envelopes, and through the personalization of each contact with the coordinators.

Dillman (2000) recommends five principles for achieving high response rates in survey research. They are: (1) a questionnaire that is designed in a respondent-friendly manner; (2) no more than five contacts with the questionnaire respondent; (3) including a stamped return envelope; (4) correspondence that is personalized, and: (5) a token financial incentive. I used four of these five elements. I did not use token prepaid financial incentives. The research on the benefits of token or financial incentives is conflicting. Since the survey respondents are State employees, and the information asked on the questionnaire is not opinion-based, but facts on each States' policies on Child Find / public awareness activities, I did not use token or financial incentives.

SurveySolutions Express is the leading provider of survey systems to the corporate and education market, and was used in this research. (See Appendix F for the questionnaire.) A marketing expert with user-friendliness in mind designed the layout for the web-based questionnaire. When the respondent clicked on the link provided through an email, the questionnaire was brought up immediately. There were no graphics on the questionnaire, and the respondent could easily move from question to question at their own speed. The respondent was able to answer the questions in any order and was provided with the opportunity to skip questions and leave questions unanswered.

There were six questions that invited the respondent to answer using a text box. The text box provided unlimited space to give the respondent the freedom to answer the question to the depth they felt appropriate. As indicated earlier, several individuals tested out the web-based questionnaire to make sure no technical difficulties were encountered. Only one respondent indicated difficulty with the web-based questionnaire, and preferred to fax the completed questionnaire.

Dillman's second principle encourages survey researchers to make up to five contacts with the respondents, and the fourth principle is personalization of correspondence. Each of the five contacts I made with each coordinator were personalized. I sent an initial letter explaining the purpose of the research, the IRB consent form, and the date the respondent should expect to receive the link to the web-based questionnaire. Each letter was on University of Maryland letterhead and personalized to include the name of the Part C coordinator, and a reference was made to their particular State (See Appendix G.)

Two weeks later, each coordinator received a personalized email sent only to that individual, with reference to their State, and the link to the web-based questionnaire (See Appendix H.) This yielded 10 responses.

The second contact included a phone call to the coordinators who did not respond to the survey. If the coordinator was not available, either a voice mail message was left, or a message was left with the administrative assistant. In addition to the phone call, a personalized email was also sent to the coordinator with a second link to the web-based questionnaire. (See Appendix I for the second email sent to the Part C coordinators.) The second contact yielded nine responses, and three additional States indicated they were not going to be responding.

Next, mailings were sent to two coordinators who requested hard copies of the questionnaire. I sent a mailing to a third coordinator, who after multiple email bounce backs and no voice mail, never received the questionnaire. The US territory Part C coordinators also received a copy of the questionnaire in the mail, because I was unable to reach them by phone. They received emails with links to the questionnaire, however at the time of the mailings, no questionnaires were completed.

The third contact was made 22 days after the initial contact. I made a phone call along with an email with the link to the web-based questionnaire. (See Appendix J for the email sent to the Part C coordinators.) As with the first phone call, I left a personalized message with either the administrative assistant or on voice mail. The third contact yielded six responses. The fourth contact was a mailing to the 17 States that had yet to respond to the questionnaire. (See Appendix K for the letter sent to the Part C coordinators.)

From a social exchange perspective, switching methods from emails and phone calls to sending the questionnaire in the mail could raise new possibilities for communicating greater rewards and increased trust. Using the mail mode format offered an opportunity for the respondent to receive new information in a new way; allowing the coordinator to see the University of Maryland stationary which could encourage trust and legitimization. Evidence indicates that people prefer different modes and if such preferences are significant, then people who have not responded to one mode because they dislike it may be receptive to a change in approach. It is logical to use different appeals at the early (email) and late (postal mail) responders.

Finally, the fact of switching from email to postal mail may help emphasize the importance of the study, encouraging trust (Dillman, 2000).

I made the fifth and final contact 42 days after the initial email. The final contact was a phone call and a final email with a link to the web-based questionnaire. (See Appendix L for the final email sent to the Part C coordinators.) A total of 33 (65%) questionnaires were returned from the US States, and 1 (20%) questionnaire was returned from a US territory.

Data Analysis

To interpret the findings of the questionnaires, a simple frequency method of data analysis was used. The data were electronically transferred from the questionnaire website to Microsoft Excel and SPSS for analysis. I conducted frequency counts on the responses to determine the commonality and/or uniqueness of each response. All data were reported and analyzed confidentiality so as to protect the identity of the State coordinators. I report the data in aggregate form.

I compared the data from the analysis of the State and territory policies and the public awareness plans a state-to-state basis in terms of each variable of the policy/plan analysis. I tabulated frequency counts and percentages on each variable and I report based on the commonality and/or uniqueness of each score. The state surveys are not compared to the scores from the policy and public awareness plans due to the aggregate format of the data and confidentiality of the State coordinators.

Chapter 4: Results

For the purpose of this research, I used three different data collection measures: 1) an analysis of State policies related to Child Find / public awareness activities; 2) an analysis of State public awareness plans related to educating the medical community on early intervention; and 3) a survey of State level Part C coordinators on the State's Child Find / public awareness efforts related to educating the medical community. First, I present the results of the policy and plan analysis followed by the results of the survey research.

Policy Analysis

The first component of data analysis consisted of an investigation of each State's policy related to Child Find / public awareness activities to the medical community. All of the fifty State policies, and the policy from the District of Columbia (n=51) were obtained from the RRFC (Regional Resource and Federal Center) Network. I was unable to obtain any policies for the US territories.

I show the results of the State policy analysis in Appendix M. Of the 50 States, and the District of Columbia (n=51) nine States (18%) did not mention Child Find / public awareness activities in their policies (California, Florida, Kentucky, Massachusetts, Michigan, Mississippi, New York, North Dakota, and Wisconsin).

I scored each State policy on five different variables. A score of 2.5 was the highest score for each variable. Out of a total of 12.5 points, only six States (Missouri, Idaho, New Hampshire, Oklahoma, South Dakota, and Vermont) received a score of 6 or above. No State policy received a perfect score of 12.5.

A number of general findings were revealed in the policy analysis component of this research. First, 48 States (94%) make Child Find and public awareness activities the responsibility of the LEAs (Local Education Agencies), school districts, or other public agencies. In other State policies, Child Find materials are developed at the State level, but implemented at the local levels. It is the State's responsibility to oversee and monitor these efforts at the local levels. For example, in Maryland's policy, the Department of Education (the lead agency) and the Maryland Infants & Toddlers program publish an annual State-wide public awareness plan. However, the LEAs implement the State plan on a local level.

Second, three States only mentioned Child Find efforts for children ages 3 to 21 (Alaska, Arizona, and New Jersey), and there was no mention of public awareness efforts for children birth to age two. Third, no State policy mentioned NICU personnel in their public awareness efforts for Child Find. Only four States (Missouri, New Hampshire, Oklahoma, and South Dakota) made reference to the medical community at all, but there was no mention to NICU personnel.

Next, I present the results for each variable in the policy analysis. The nine State policies that did not contain any information about Child Find / public awareness were not included in the counts for each variable (n=42).

Variable One – Short-term Objectives. First, I evaluated the general short term objectives related to Child Find and public awareness efforts. Of the 42 State policies, 32 States (76%) had vague or ambiguously worded objectives and there was no mention of efforts to target the medical community. An example of a policy that was vague/ambiguous was Alabama's policy which states: "Education agencies serving children with disabilities must develop and implement procedures that ensure that all children within their jurisdiction, birth to twenty-one, regardless of the severity of their disability, and who need special education and related services are identified, located, and evaluated (290-8-9.01(3)(a))."

Wyoming's policy was also vague/ambiguous. Their Child Find policy read: "School districts and agencies must implement Child Find to identify, locate, and evaluate all children with disabilities. This includes children in private schools" (Wyoming Rules, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf). There is no indication as to which agencies must participate in the implementation of Child Find, or what is defined as Child Find.

Seven states (Arkansas, Colorado, Illinois, Maine, Oklahoma, Oregon, and Vermont) had policies that were clear and concise but did not mention targeting the medical community. For example, Vermont's Child Find policy is divided into two sections. The first section is for infants birth to two years of age, and the second section is for children ages 3 to 21. The policy further states that the State is divided into 12 regions and Child Find is a joint responsibility of the local school district and other local public agencies which is explained in the State's Regional Plan for the implementation of Early Intervention Services (Vermont Rules, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Maine divides their Child Find objective into nine different parts, including general principles, responsibilities, elements, responsible staff, local policies and records (Maine Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf). Colorado also divides their policy into different sections including coordination and implementation, and planning and development. The policy clearly states that Child Find is "the responsibility of the administrative unit in which the child attends school, or, if (s)he is not enrolled in school, it shall be the responsibility of the administrative unit in which the child resides" (Colorado Code 2220-R-4.00, 4.01, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Only three states (Missouri, New Hampshire, and South Dakota) had clear and concise short term objectives that contained information targeting the medical community. Missouri's policy states that the Department of Elementary and Secondary Education is responsible for coordinating the planning and implementation of Child Find activities for children birth to 21. Missouri is only one of three states that does not make Child Find the sole responsibility of the LEAs. Missouri's Child Find policy outlines that four other State agencies must participate in the planning and implementation of Child Find activities. The Department of Mental Health must assist in identification of infants and toddlers through its Regional Centers for the Developmentally Disabled, State Habilitation Centers, and State Hospitals. The Department of Health must assist in the identification through its Title V and Head Injury Programs. The Department of Social Services has three departments also required to assist in Child Find activities: Division of Family Services, Rehabilitation Services for the Blind, and the Division of Youth Services. Finally, the Missouri policy on Child Find also enlists help from the Department of Corrections in identifying eligible children placed within its jurisdiction (Missouri Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

In their Child Find policy, New Hampshire has a specific section for children placed in homes for children, Health Care facilities, or State Institutions. The policy outlines that an LEA employee be appointed to direct the Child Find effort and must contact, at least annually, agencies including the DCYF, DYDS, local public defenders, local district courts, residential and treatment programs, and social service agencies that provide mental health, medical, welfare, and other human services (New Hampshire Rules, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Similar to Missouri and New Hampshire, South Dakota outlines other agencies to assist in Child Find efforts. The policy explains the division's responsibility to coordinate with other State agencies responsible for administering health, education, and social service programs including maternal and child health care programs, Medicaid, and Head Start (South Dakota Rules, retrieved from http://doe.sd.gov/oess/specialed/index.asp).

Overall, 76% of the State policies (32 of 42) have vague objectives related to Child Find and public awareness. Of the 32 States, in 12 cases (Alabama, Connecticut, the District of Columbia, Georgia, Hawaii, Iowa, Minnesota, Montana, Nebraska, New Mexico, Texas, and Wyoming), this is their only mention of Child Find and public awareness activities. Each received a score of "0" on the remaining four variables.

Variable Two – Materials and Efforts. I evaluated types of public awareness materials and efforts to promote Child Find for the second variable. Twenty-three out of the 42 States (55%) mentioned public awareness materials and/or efforts. In the 23 State policies, 11 (Alaska, Arkansas, Arizona, Colorado, Kansas, Louisiana, Maryland, Nevada, Pennsylvania, Tennessee, and Virginia) had a vague mention of public awareness materials or efforts with no mention of efforts targeting the medical community. Many of these States simply mentioned that they would develop materials and conduct public awareness activities; however there was no further mention of what the materials and activities would be.

Kansas had a vague State policy. It states that "each board, at least annually, shall provide information to the public concerning the availability of special education services . . . (Kansas State Regulations 91-40-7.(2)(B)(d))."

Another example can be found in Louisiana's policy which states that "notice of the child identification effort regularly undertaken by the Department and Local Education Agencies shall be published or announced in newspapers or other media with circulation adequate to notify parents throughout the State (Louisiana Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf)". Virginia's policy states that the local school division must show evidence of the use of a variety of materials and media in their Child Find efforts (Virginia Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Although New Hampshire's policy made vague mention of public awareness materials and efforts, there was reference to targeting the medical community. Specifically the policy mentions that " . . . the LEAs shall annually contact all social service agencies within its jurisdiction which provide medical, mental health, welfare, and other human services (New Hampshire Rules Ed1103.02(d))" about Child Find activities.

Six States (Idaho, Indiana, Missouri, Ohio, Vermont, and Washington) have clear and detailed information related to what materials will be developed and/or disseminated, however there is no mention of the medical community. For example, the Idaho policy states that "by November 1, the district will take necessary steps to make sure that the staff and general public are informed on the availability of special education services, student rights, confidentiality measures, and the referral process." The policy further states that this information "may be provided through a variety of measures including brochures or flyers, articles and announcements in newspapers, arranging time for radio and television messages and appearances, as well as speaking at faculty or district in-service meetings" (Idaho Code 16-103 (11-12)).

Oklahoma was the only State that mentioned the medical community in their public awareness efforts and material distribution. The policy outlines that each LEA will appoint an individual to coordinate and implement public awareness and Child Find activities. Their public awareness process involves the documentation of a minimum of two ongoing/periodic activities including advertisements; public service announcements; placement of referral cards or posters in public places including doctors' offices, hospitals, and pharmacies; mailings including brochures, newsletters, or pamphlets; video presentations; or public forums (Oklahoma Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Overall, only 19 States (45%) mention specific types of public awareness activities and efforts. Of these 19, only 2 mention the medical community (New Hampshire, and Oklahoma). New Hampshire's policy also mentioned the medical community in their short term objectives.

Variable Three - Dissemination. I evaluated a description of information dissemination for variable 3. The policies in 15 States (Alaska, Arkansas, Arizona, Idaho, Indiana, Kansas, Louisiana, Ohio, Oklahoma, Pennsylvania, Tennessee, Virginia, Vermont, Washington, and West Virginia) had a minimal description of the recipients of the public awareness efforts, without any mention of the medical community. For example, Louisiana and Pennsylvania policies state that there will be publications in newspapers or other media with adequate circulation to notify parents throughout the State. Virginia's public awareness efforts are directed to the community as a whole, and Washington's efforts are geared toward educational staff and parents.

Although New Hampshire's policy had only a minimal description of to whom the information would be disseminated, it did mention the medical community, including social service agencies that provide medical, mental health, welfare and other human services.

Missouri's policy was more specific on this variable. In their policy, there was a clear description of who would receive the disseminated information, however there was no mention of the medical community. In the policy, the public awareness activities are directed to the general public, teachers, administrative staff, and parents. Although they clearly describe whom they are targeting and what activities they will use for each population (see variable two), there is no mention of the medical community (Missouri Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

South Dakota's policy stood out on the third variable. The policy was stated very clearly, indicating whom they are targeting for Child Find / public awareness activities. The policy states that they will develop a communication system with primary referral sources to promote Child Find. Hospitals, including prenatal and postnatal care facilities, physicians, community health facilities, and other licensed health care providers are all listed in South Dakota's policy (South Dakota Rules, retrieved from http://doe.sd.gov/oess/specialed/index.asp.)

Overall, only 18 State policies contained references about who was targeted in their Child Find efforts. Of these 18 policies, only 2 (New Hampshire and South Dakota) mentioned the medical community. New Hampshire's policy mentions the medical community in their objectives, what activities will be done as well as who those activities will be directed towards (variables one, two, and three). South Dakota's policy also contains a reference to the medical community in their objective. Although they clearly indicate that they will direct their activities to the medical community (variable three), they made no mention of what those activities would be (variable two).

Variable Four - Timeline. For the fourth variable, I evaluated the time line for disseminating materials. The policy in eight States (Kansas, New Hampshire, Oklahoma, Oregon, Pennsylvania, Virginia, Vermont, and West Virginia) had a vague timeline for dissemination of materials/efforts, and no mention of the medical community.

Three States' policies (Oregon, Idaho, and Missouri) had a clear timeline for the dissemination of materials and public awareness efforts but did not mention the medical community.

Missouri's policy outlines that by November 1 there must be one public notice in local newspapers describing the LEA's responsibility to identify and refer infants and toddlers suspected of having a disability to the early intervention system. They must also air one public notice on a local radio or television station during general viewing / listening hours. Posters and notices must be placed in all administrative offices of each building operated by the school system and written information must be given to parents / guardians of children enrolled in the school district by November 1 (Missouri Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Variable Five - Evaluation. In the fifth and final variable, I investigated information on short term objective evaluation. Of the 42 States, 10 (Colorado, Idaho, Louisiana, North Carolina, New Jersey, Rhode Island, South Carolina, South Dakota, Utah, and Virginia) had an ambiguous or vague description of evaluation efforts without mention of the medical community.

For example, Utah's policy states that the Utah State Department of Education will conduct on-site monitoring of the Child Find procedures through a regularly scheduled monitoring process (Utah Code, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf). In Rhode Island, the policy states that there will be a description of how the policy and procedures will be monitored

(Rhode Island Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf), although no description is provided.

Missouri had clear evaluation measures but still no mention of the medical community. No State policy contained a reference to evaluating short-term objectives related to the medical community, which is not surprising since only three State policies contained information on the medical community in their short-term objectives (variable one).

Missouri's policy is clear, concise, and detailed in their efforts to monitor and evaluate Child Find / public awareness efforts. The policy states that by December 15th of every year, each local school district must aggregate all census data as of December 1st, and report the data to the Missouri Department of Elementary and Secondary Education. The Department of Elementary and Secondary Education will then monitor the implementation of Child Find requirements including approving each local district's Compliance Plan documentation, and by reviewing the data from each district's annual census report (Missouri Regulations, retrieved from: http://128.146.206.2331/Resources/NSPD.cmf).

Policy Analysis Conclusions. After thoroughly reviewing each State's policy on Child Find and public awareness, a number of factors stood out. First, it is surprising that nine States had no mention of any State required Child Find / public awareness efforts. Second, the overwhelming majority of the State policies had vague and ambiguous objectives related to Child Find; most only contained a sentence indicating that it is the LEAs' responsibility to locate and refer eligible children to Child Find. Third, it appears from this review that only four States had any mention of the medical community in their public awareness efforts. Fourth, there was no mention in any State policy about public awareness efforts to the NICUs.

Public Awareness Plan Analysis

The second method of data collection consisted of an analysis of the States' public awareness plans as they relate to educating the medical community about Child Find and early intervention. As outlined in P.L. 108-446, the IDEA Reauthorization Act, States are required to have a comprehensive child find system, and a public awareness program. The child find system must include procedures for making referrals to early intervention, and must provide for participation by the primary referral sources. Under the public awareness program requirements, States must prepare and disseminate information related to the availability of early intervention services to all primary referral sources, especially hospitals and physicians who provide care for premature infants (118 STAT. 2747). States are not required by federal law to have a written public awareness "plan" per se, however many States do have such a plan.

Before the questionnaire was sent to the Part C coordinators, I sent an email to the state ICC chairs requesting a copy of the State's public awareness plan. I received only two plans. In the questionnaire, if the respondent reported his/her State had a public awareness plan, I requested a copy of the plan. I received only four plans from the survey respondents. I received and analyzed a total of six public awareness plans. Although the number of plans is low, the information obtained from the plans provides an addition glimpse of State-level Child Find efforts to the medical community from the States that provided them.

I received public awareness plans from the following states: Connecticut, Florida, Idaho, Michigan, Texas, and Wyoming. I analyzed each plan in the same manner as the State policies (see Appendix N for a side-by-side analysis of the State policy scores and the public awareness plan scores). Although only six plans were received, the results of the analysis are important in that the public awareness plans received scores that were much higher than the scores from the policy analysis. Each public awareness plan contained more information related to objectives, activities, timelines, intended audiences, and evaluation efforts. Investigating the public awareness plans provides an additional lens through which to view State-level Child Find efforts.

Connecticut received a score of “1” on the policy analysis, but received a total score of “12.5”, which is the highest score, on the public awareness plan analysis. Connecticut’s policy contained a vague short-term objective with no mention of the medical community. This could lead one to believe their Child Find efforts, in general, are inadequate. However, an analysis of the public awareness plan revealed a very detailed effort to promote Child Find and early intervention to the medical community. This finding is similar to the results of the other five public awareness plan analyses.

Representatives from Connecticut submitted their Marketing Plan for the 2004-2005 fiscal years. The plan was six pages long and divided into five sections. Under the second section, numerous action and maintenance steps were provided.

Included in their action steps was a step to disseminate educational materials to pediatricians, family practice physicians, Advance Practice Registered Nurses, and hospitals and NICUs. The material the state provides to these physicians includes a written letter of explanation of the early intervention program and a list serve announcement and newsletter article from the AAP. This objective was very clear and detailed, and included the medical community, thus giving the state a score of 2.5 on the first variable.

Under their maintenance steps, they provide early intervention products to organizations that serve low-income / underserved populations including community health clinics, and well-child clinics. Since the plan explains exactly who will be receiving the information (pediatricians, family practice physicians, nurses, hospitals, clinics, and especially NICUs) and what they will be receiving (letter of explanation, AAP list serve announcements and articles); the plan received a score of 2.5 for both variables two and three.

The third section contains action steps for data analysis. Their steps include reviewing physician referral data for annual trends, including the total number of physicians providing referrals, any change in the number of referrals per physician, any change in the age of the child at the time of referral per physician, and whether there is any geographic difference in the numbers of physicians making referrals to early intervention. Also included in their action steps is an in-depth analysis of children who are referred before one-year of age, including identifying and remediating any possible gaps. This was by far, the most detailed objective evaluation of any public awareness plan or policy reviewed in this research. This state received the highest score of 2.5 for the fifth variable, objective evaluation.

Their fourth section includes action steps for collaboration with other initiatives. There is also a step for coordinating referral source training and outreach strategies with the Department of Public Health. A specific date was provided for when the public awareness efforts must take place, thus giving them a score of 2.5 for the fourth variable. Overall, Connecticut's public awareness plan was very detailed in all variables especially the fifth variable of objective evaluation.

Connecticut's policy made no mention of the medical community in their vague description of the Child Find efforts; however, the public awareness plan contains information related to not only the medical community in general, but also NICU personnel. The plan is detailed in every variable that I analyzed and presents a more thorough picture of the Child Find efforts in the State of Connecticut than the policy.

As with the State of Connecticut, to get a better idea of what Florida is doing to promote Child Find to the medical community, and in general, one must look at the public awareness plan instead of the State policy. Florida's policy did not contain any reference to Child Find or public awareness; however their public awareness plan contains detailed information.

Included in Florida's public awareness plan for the 2005-2006 fiscal year were products / events, targeted audiences, and the timeframe for each. There were 13 sections describing their products and events. Of these 13 efforts, 4 contained the medical community in their targeted audience. In addition to the medical community, nursing schools, newly licensed physicians, and pediatricians were also listed.

Their products / events targeting the medical community included locally customized print ads placed in local family resource guides and child care handbooks. General brochures with information on child find activities and community awareness were also listed. These brochures are to be distributed specifically to the newly licensed physicians and health care providers. Their last product / event is to research costs and options for a program videotape to disseminate to the medical community.

Since Florida's plan has specific objectives related to working with the medical community, the specific members of the medical community they are targeting (nurses, newly licensed physicians, pediatricians, and other health care workers), and specific materials and public awareness efforts that will be done to target this community, I gave a score of "2.5" for the first three variables. A time frame was also provided for each product/event. The time frame is divided into seasons (e.g., by summer 2006). For this reason, I gave a score of "2.5" for the fourth variable. There was no mention of objective evaluation or monitoring, so a score of "0" was given for the fifth variable.

Unlike Connecticut and Florida, Idaho's policy related to Child Find and public awareness activities was adequate. Although there was no mention of the medical community in Idaho's policy, the plan does include the medical community.

Idaho's plan lists two broad goals with numerous action plans describing the activities necessary to achieve the broad goal. Also outlined in their plan is the person responsible for each action plan objective along with a specific date (e.g., March 2006) a section for progress toward the objective, and the next steps to be taken.

Idaho's plan has three action plan objectives that relate to the medical community. Their first objective is to identify organizations and stakeholders who provide prenatal information and services. They list obstetricians / gynecologists as an example of their resources. A second objective in their plan is to gather and review existing material that they are currently disseminating statewide in the prenatal areas. Their third objective, related to the medical community, is to research effective nationwide materials and models to supplement their existing resources as needed.

Representatives from Idaho also provided their ICC and Infants and Toddlers' Program progress report for 2004-2005. In the report, which is in the form of a booklet, the ICC co-chairs indicate they are out of compliance with the federal requirements to provide timely services for eligible infants and toddlers. Their report includes perspectives from families and general information about early intervention.

In addition to the public awareness plan and progress report, representatives from Idaho also sent their State plan to help coordinate resources, skills, and expertise in early intervention in the local communities across the State. They provide 10 shared goals for early intervention initiatives and an outline to integrate services, and a timeline from December 2005 through August 2008. They have six focus areas including health care.

Idaho's plan received a score of "2.5" on the first four variables. They were very clear about whom they were targeting (including the medical community), and when and what they were going to do. They do clearly mention for each global action plan progress made, and next steps. For some of the accomplished action plans they evaluated their plans through collaborative meetings and material reviews.

Idaho not only has information in their State policy related to Child Find, they also have a very detailed and comprehensive public awareness plan to promote Child Find to the medical community. Although there is no mention of NICU personnel, obstetricians and gynecologists are medical specialists that are mentioned in the public awareness plan.

Similar to Florida, Michigan's policy did not contain any reference to Child Find or public awareness activities. It appears that the early intervention staff does not place much emphasis on Child Find in their policy; however, a marketing firm was hired to design and help implement their public awareness plan.

Michigan's public awareness plan is a 32- page document containing background information, overall objectives, target audiences, campaign tactics geared specifically for that audience, and an extensive resource list including professional organizations, primary referral / professional association publications and meetings / conferences in their state. One of the target audiences is primary referral sources including physicians.

In this section of their plan, they report the number of health care practitioners and support workers in their State. They list the numbers of general practitioners, general internists, general pediatricians, registered nurses, licensed nurses, and nursing aides. They also list the number of recognized hospitals and urgent care systems.

Strategies for reaching primary referral sources includes a recommendation that the early intervention agency contact the providers about whether they have a state-distributed newsletter or publication, mailing list or if they have annual meetings or conferences in order for the early intervention system to distribute their publications and attend meetings. They further list a variety of "deliverables" including posters, brochures, rack / counter cards to be displayed at check-out counters in physicians' offices, emergency rooms, and urgent care clinics.

Although Michigan's plan is very detailed and filled with information on reaching out to the medical community, there was not a clear objective for doing so. Thus, the plan only received a score of 1.5 on the first variable. However, they are explicit on the materials to be provided to physicians, and events / advertising that will be done. For this reason, they received a score of 2.5 on the second variable. They also received a 2.5 for the third variable because they provide the number of physicians, pediatricians, and other health care providers practice medicine in their state and who is the target for their Child Find efforts. They also list the number of hospitals. No other public awareness plan provided this much detail on the medical community.

Michigan's plan further includes the dates and time frames for various medical trade shows, conferences, and meetings, therefore, receiving the highest score of 2.5 for the fourth variable. For the fifth variable, information on objective evaluation, the state received a score of zero. Although the plan was remarkably detailed, there was no mention of how the State would evaluate the effectiveness of these efforts.

Although Texas' policy was vague, the public awareness plan provides a much better insight to the State-level Child Find efforts. The public awareness plan for Texas contained four broad goals to improve their public awareness plan and each goal contained objectives and strategies to achieve these objectives. Each goal and its objectives were clear, thus they received a score of "2.5" for variable one. A specific objective in the plan included increased outreach to families of premature infants and the medical referral sources who work with these newborns and their families. They planned to investigate statewide outreach efforts to hospitals and PICUs and to develop materials for distribution to the families of premature infants. This is accomplished with the collaboration of the March of Dimes and the State's Pediatric Society.

The plan only vaguely mentioned materials that they would distribute, however, they did reference the medical community, thus I gave them a score of "1.5". They were very clear in that they were targeting families of premature infants and the medical community that works with them, thus I gave them a score of "2.5" for the third variable. Their timeline was vague in that they only referenced a year's time span as opposed to specific dates, and I gave them a "1.5" for the fourth variable. They made no mention of evaluating or monitoring the effectiveness of their efforts and received a score of "0" for the fifth variable. The public awareness plan for Texas contains the only reference to the new component of IDEA requiring states to specifically target families of premature infants in their Child Find efforts.

I received the final public awareness plan from Wyoming. Similar to Connecticut, and Texas, the only mention of Child Find and public awareness in

Wyoming's policy was a vague objective with no mention of the medical community. Their public awareness plan also contains no mention of the medical community, but it does provide more information on the State Child Find efforts.

Wyoming's plan includes a very detailed description of their objective which is actually three separate objectives including implementing a statewide marketing campaign, raising awareness among parents of the importance of screenings, and involving other organizations in these efforts. For the second variable, they include information on radio ads, local mini-grants, and printed materials they will use to advertise their program. In addition to disseminating this information to families, they also mention specifically targeting Native Americans and the Latino population. However since they mention families but not the medical community, I gave them a score of "2" for the third variable. I gave the fourth variable a score of "1" because although the plan contains a date, it is rather vague and covers a one-year period. The plan does reference how they monitored the elements of their program over the past year and will continue to do so; however they do not indicate how they plan to do so in the future. I gave this plan a score of"1" for the fifth variable.

In each of the six states that provided their public awareness plans, detail is provided in the State-level efforts to promote Child Find to the medical community. In looking at the policies alone, one might infer that these states do not have the comprehensive Child Find program, as outlined in IDEA. However, to get a more clear description of these Child Find efforts, the public awareness plans provide the detail that is missing in the State policies. To gather more information on this topic, the questionnaire sent to the Part C coordinators contained four additional questions related to State public awareness plans.

The analyses of the State policies, and the public awareness plans were designed to assist in answering the first two research questions related to what the States are doing in their Child Find efforts to the medical community, and how are the States evaluating the effectiveness of these efforts. The public awareness plans provided more comprehensive information related to State-level Child Find efforts, and evaluation methods compared to the State policies. The majority of the policies were vague in their Child Find programs however the public awareness plans provided more detail about the State-level Child Find efforts.

Survey Analysis

I designed the survey component of this study to help answer all three of the research questions. The questionnaire included questions related to State-level ICC information, and collaboration efforts, along with information on public awareness plans, referrals, efforts to reach out to the medical community and barriers that prohibit these efforts.

A total of 34 (61%) questionnaires were received. Thirty-three (65%) were from the US States and one (20%) was from a US territory. Since the US territories are required to follow the same federal laws as the States pertaining to the IDEA requirements if they accept federal funds, I combined the questionnaire received from the territory with the State-received questionnaires for data analysis. Twenty-eight questionnaires were submitted on-line, four were received through the mail, one was faxed, and one was completed over the telephone. I present the outline of the questionnaire in Table 1.

Table 1

Public Awareness Questionnaire

Items	Content
1-7	Background / demographic information
8-14	State ICC information
15-21	Referral information
22-25	Public awareness plan information
26-27	Information concerning the medical community
28-30	Other information

Background / Demographic Information

In the first seven questions, I asked about the respondents' background and general information about the State's early intervention staff. This demographic information was helpful in describing the respondent and the number of employees in the early intervention programs to determine the size of the State. This information was also useful in drawing conclusions about the relationship between the size of the early intervention system, and any barriers related to Child Find efforts to the medical community.

The majority of the respondents (41%) reported they have been in their position between one and five years. The second highest percentage of respondents (38%) reported being in their position for more than five years. Only 6% of the respondents have been in their positions for less than six months (see Table 2). Since the majority of respondents have been in their positions for some time, they may have good information about their State's public awareness / Child Find efforts. However, it should be noted that although I sent the questionnaires to the Part C coordinators, they may not have completed the questionnaire. Further, during the end of the data collection period, in attempt to increase the response rate, I suggested to the coordinator that another individual knowledgeable about the State's public awareness program complete the questionnaire.

Table 2

Question Number One: How long have you been in your current position?

Number	Percentage	Response categories (n=34)
2	6%	Less than 6 months
5	15%	6 months to 1 year
14	41%	1 to 5 years
13	38%	Greater than 5 years

In the second question, I asked the respondents to provide the number of full time employees working in the early intervention program. The responses ranged from 1.5 to 350+ employees. One respondent indicated that the Part C coordinator is the only full time employee. The rest of the employees are contracted out or have additional duties. The majority (62%) of the respondents reported between 1 and 10 full time employees.

Ninety-one percent of the respondents said they have staff members whose responsibility includes public awareness activities (n=31). One coordinator said that it is the responsibility of all early intervention staff members to promote Child Find /

public awareness. This response is consistent with two other respondents who reported it is everyone's responsibility. Respondents with staff members whose responsibility includes public awareness activities were then asked to report the number of staff. The responses ranged from 0.5 to 70 staff members. The majority of the respondents (32%) had only one staff member whose responsibility includes public awareness activities.

Thirty (88%) of the respondents indicated they have staff members whose responsibility includes promoting Child Find to the medical community. Of these, six indicated the staff members who are responsible for public awareness activities are also responsible for promoting Child Find to the medical community. Another respondent said that all participate at some level.

For the final question in this section, I asked the respondents to list their State's criteria for automatic eligibility into the early intervention program under conditions of established risk / high probability category. Fourteen States said their lists are too long and said to contact either NECTAC, their State website, or their State policy to obtain this information. Interestingly, two respondents indicated they do not know or have this information. Due to the low number of responses to this question, the information is not reported.

State Interagency Coordinating Council Information

Under this section of the questionnaire, I asked about collaboration efforts with local Part C coordinators, Interagency Coordinating Council (ICC) composition, and interagency agreements. For each State, the number of local Part C coordinators varied and ranged from 0 to 96. Many States do not divide their early intervention systems into local areas. One respondent indicated their system is divided by region, and they have 10 regions. Another respondent said that their early intervention program is one program State-wide. This is consistent with yet another respondent who simply said they don't have local Part C programs. Additional questions in this section are related to collaboration between the local Part C coordinators and the evaluation of the State's public awareness plan. This information is reported in the fourth section regarding the public awareness plans.

In the next group of questions I asked about the State's ICC, who serves on the council, and information on interagency agreements. In order to receive federal funding under IDEA, States are required to have an ICC. The Governor of each State appoints the council and a member of the council to serve as the chairperson. The members of the council must include a minimum of 20% parents of children with disabilities, and 20% early intervention public or private providers. The council must also include a member from the State legislature, State Medicaid program, Head Start and child care agencies. A representative for the State regulation of health insurance and an individual representing homeless children and youth, must also serve on the council. Finally, the council must have a representative from the State child welfare agency and the State's agency for children's mental health (118 STAT. 2759). Someone representing the medical community is not required to serve on the State ICC. In the following section, I describe who serves on each State's ICC, information related to interagency agreements, as well as collaboration efforts.

Two questions were related to the composition of the ICCs. Twenty-nine (85%) of the respondents reported there was an individual representing the medical community on the State ICC. These 29 respondents were asked to provide the title(s) of the person(s) who serve on the ICC. (See Appendix O for a complete list.) Three respondents reported having a pediatrician from their State university, nine had a pediatrician, three had a developmental pediatrician, six had a general physician, one had a neonatal nurse practioners (NNP), and another had a neonatologist on their council.

It is the responsibility of the lead agency to have formal interagency agreements that define each agency's financial responsibility for paying for early intervention services. The agreement must also include procedures for resolving disputes to ensure meaningful cooperation and coordination (118 STAT. 2748). Twenty-eight (85%) of the respondents said they do not have written interagency agreements with the medical community. The five respondents (15%) who indicated they do have a written interagency agreement with the medical community were asked if there is a component in the interagency agreement related to public awareness to the medical community. Five respondents indicated there was, and five respondents indicated there was not.

Referral Information

In the next seven questions, I asked the respondents about the manner in which they collect data on referrals and where the referrals come from. Ninety-one percent (n=31) of the respondents indicated they do collect data on how many referrals they receive each year. The three respondents who reported that they do not collect these data were directed to the next section of the questionnaire.

I asked the respondents to provide the number of referrals they received to the early intervention program for the 2004 fiscal year. One respondent reported they only have data for those found eligible and did not provide a number. Two other respondents also reported they only collect data for those found eligible and their numbers ranged from 1,395 to 3,039. For the remaining 23 responses, the number of referrals ranged from 1,203 to 50,000.

All respondents (n=34) reported collecting data on the referral source, however only 56% (n=18) collect data on referrals specifically from NICUs. Ninety-four percent (n=30) reported collecting data on the number of referrals from medical-related institutions (e.g., hospitals, medical centers, pediatrician's offices).

In the next question, I asked the respondents to list the various sources from which they receive early intervention referrals and the number of referrals received from each source. Twenty-five (74%) of the respondents provided this information. Of these, five respondents listed the source of the referral but did not provide the number received from each source.

An additional seven respondents indicated they do not have the time to report this requested information, or they have not analyzed these data on a State-wide basis. Another respondent indicated they have done a pilot study tracking the referral data with only five counties, however they did not provide their data. Another respondent said they have only recently developed a data management system to track their referrals and before this new system, they did not have any systematic way of tracking or managing the data.

Public Awareness Plan

There were four questions related to the State's public awareness plan and how States educate the medical community on Child Find and early intervention services. Twenty-three respondents (70%) reported they have a general public awareness plan, and 10 respondents (30%) reported they do not have a plan. One individual did not respond to this question. Of the 10 States that do not have a public awareness plan, it is interesting to note that all respondents reported collecting data on how many referrals they receive each year; however four did not provide any additional information.

In the next question, I asked the respondents if there are specific guidelines in their public awareness plan to promote early intervention to NICU personnel, pediatricians, family physicians, the general medical community, and other specialists. Sixty-five percent reported having information to educate NICU personnel in their plans, and 83% reported having information to educate pediatricians. Eighty-two percent have information targeted at family physicians, and 86% have information related to educating the general medical community. Finally, 65% have information specifically directed toward educating other specialists.

Next, I asked the respondents to provide the titles of the persons who develop the State public awareness plan. The responses to this question varied greatly and included Child Find coordinators, Part C coordinators, Statewide ICC members, public awareness and Child Find coordinators, and local agencies. The responses to this question are found in Appendix P.

In the final question of this section, I asked the respondents if they provide any public awareness activities that target the medical community. Twenty-seven

(90%) of the respondents indicated they have, and three (10%) indicated they have not provided any activities directed to the medical community. Brochures and flyers were the most frequently reported activity. Other respondents reported the following activities: participation in the medical community meetings, collaboration with the State Chapter of the AAP, and participation in bi-weekly pediatric rounds. Finally, a respondent explained they distribute brochures with a cover letter from the chairperson of the State Association of Pediatrics endorsing early intervention (See Appendix Q for a complete list of the activities from each of the respondents).

The following two questions were listed in the State ICC section of the questionnaire, but I report the results here because they relate to public awareness plans. I asked the respondents to what extent they collaborate with their local Part C coordinators to evaluate the effectiveness of their public awareness plans. (See Table 3.) Thirty-two respondents provided information; however, in a previous question, only 23 States reported having a public awareness plan. Routine collaboration was the most frequently reported answer at 51%. One respondent was unsure, and three did not provide an answer to the question.

Table 3

To What Extent do you Collaborate with your Local Part C Coordinators to Evaluate the Effectiveness of your State Public Awareness Plan (n=32)

Response	Percentage	Frequency
Routine collaboration	53%	17
Occasional collaboration	31%	10
Rare collaboration	0%	0
No collaboration	13%	4
Unsure	3%	1

In the next question, I asked the respondents if they collaborate with their local Part C coordinators, how they do so. Monitoring efforts (59%) was the most frequently reported answer. A few respondents provided additional information. One respondent reported they have a State ICC subcommittee which reviews data on public awareness and Child Find activities. Another respondent explained they survey each local office annually on public awareness needs and related items. Only 29 respondents previously reported they have local Part C coordinators.

Information on the Medical Community

The next two questions related specifically to the medical community. Eighteen (60%) respondents reported they ensure that NICU personnel inform parents about early intervention. Twelve (40%) of the respondents reported they do not, and four respondents did not answer the question. If the respondent indicated that they do ensure that NICU personnel inform parents, they were then asked to explain how they determine the extent to which this information is made available to parents. Twenty-one respondents provided information. The three respondents who reported they don't ensure that NICU personnel inform parents about early intervention provided additional information as well.

One respondent explained that an early intervention staff member attends weekly discharge rounds at two different hospitals. They are often able to write the IFSP (Individualized Family Service Plan) before the infant leaves the hospital. Another respondent reported that the State funds a project to work with staff in level III nurseries and to assist staff in making referrals to early intervention. Another respondent reported that in one State, they receive quarterly reports from the NICU as to the number of early intervention referrals made. Finally, one respondent explained that intake staff members are located within hospitals with larger NICU (See Appendix R for a complete list of how states ensure that NICU personnel inform parents about early intervention).

Other Information

The last three questions related to general information on birth defects registry, and possible barriers to promoting early intervention to the medical community. The final question was open-ended and asked the respondent to detail what assistance they may need in implementing the new clause in the IDEA amendments.

Twenty-three (74%) of the respondents reported their State has a birth defects registry. Five (16%) responded their State did not have a registry; three (10%) were unsure, and three did not respond to the question. As discussed earlier, a birth defects registry is a surveillance program that is designed to track children with birth defects and identify those who would qualify for early intervention (Farrell et al., 2003).

In another question, I asked the respondents to report the barriers to promoting early intervention to the medical community. The three most frequently named barriers were lack of time, staffing issues, and access to the medical community. (See Table 4.)

Seven respondents provided additional information. One respondent reported their State has addressed most barriers; however, because responsibility for implementation occurs at the local levels, some communities are better than others at ongoing outreach to the medical community. Willingness of the medical community to follow through with referrals is a problem in one State, and another reported there is a lack of understanding that children need developmental services in addition to medical care. Another respondent suggested that changes need to occur to encourage the medical community to refer when the family suspects a delay instead of employing a "wait and see" attitude. This respondent also suggested promoting collaboration with the early intervention teams and the child's primary caregiver.

A final respondent reported that in her/his State, they have been experiencing a large number of referrals through the CAPTA (the Child Abuse Prevention and Treatment Act) legislation and the local services areas are swamped with more referrals and additional children to evaluate. This has caused them to have less time to do outreach with the local medical community.

Table 4

Barriers to Promoting Early Intervention to the Medical Community

Response	Percentage	Frequency
There are no current barriers	6%	2
Funding/financial issues	50%	17
Training issues	41%	14
Lack of time	65%	22
Staffing issues	62%	21
Access to the medical community	59%	20
Other	6%	2

The responses in the final question provide useful information as to what the States need in order to promote Child Find and early intervention to the medical community. Twenty-one respondents provided information. One respondent would like to receive information about the way prematurity affects development and needs assistance to understand who would be the contacts at the birthing hospitals. Other respondents would like information on ways to access the medical community, information about successful modes of public awareness, and effective education campaigns to the medical community. The respondent also suggested the use of internet-based learning modules. This is somewhat similar with the response of another who would like to have a brochure template that States could use and adjust as necessary and disseminate.

Another respondent would like more funding to help local programs in their public awareness activities. This person explained that currently service coordinators have the primary responsibility for public awareness in addition to their caseloads of families. A few respondents reported that additional staff members as well as staff time to devote to an ongoing cycle of direct, on-site training, and outreach would be very helpful.

A few respondents wanted to know what the AAP is doing to address the problem. One respondent explained that their State is still receiving parent comments indicating that physicians still don't see a value to a "don't worry, but don't wait" philosophy when it comes to referrals of young children. The respondent explained that a few physicians are still telling families that premature infants will grow out of things and suggested that more information in medical school was the key.

Another respondent suggested national efforts directed towards all well-baby medical providers, in addition to collaboration at the nation level between Part C and the AAP regarding best practices. It was suggested that the medical community needs to offer CEUs (Continuing Education Units) for training and follow-up screening that can be co-offered with early intervention. Also suggested were internships with early intervention and developmental assessments.

A few respondents simply indicated that any and all assistance would be helpful, or that it would be useful to have examples from other States. One respondent summed up the views of a variety of respondents with the comment, "Additional suggestions on activities are always appreciated, but if resources in personnel and funding are not available to implement the activities, implementation is not possible." Only two respondents that provided information in this final question said they do not need any additional assistance.

Each method of data collection, the policy analysis, public awareness plan analysis, and the survey research all contributed to answering the three research questions in this study. Although each method has limitations, the information obtained in this study adds to the limited research on Child Find and public awareness.

Chapter 5: Discussion

In this chapter I address three research questions by summarizing findings from the three methods of data collection, discuss limitation of the research, implications for future research and implications for practice. The purpose of this study was to investigate: 1) what the States are doing to promote Child Find and early intervention to the medical community through public awareness efforts; 2) how the States are evaluating the effectiveness of these efforts, and 3) what are the perceived barriers in promoting Child Find and early intervention to the medical community. I answered the three questions using three different methods of data collection. The first was an analysis of each State's policy on Child Find and public awareness efforts to the medical community. The second was an analysis of the public awareness plans from the States that submitted them. The third was a survey sent to the State's Part C coordinator.

Question 1: What are the Part C lead agencies doing to promote Child Find and early intervention to the medical community in general and more specifically NICU personnel?

To answer this question, I used data from all three research methods. The State policies, in general, contained little if any information related to Child Find efforts; however, the plan analysis and the survey suggest that the States are taking a variety of approaches to promote Child Find to the medical community.

To promote early intervention and Child Find to the medical community, a few States enlist the help of other health agencies. Missouri, for example collaborates with the Department of Mental Health, Regional Centers for the Developmentally

Disabled, and the Head Injury Program. Texas collaborates with the March of Dimes and the Texas Pediatric Society in their public awareness efforts. In Connecticut, the Department of Health is a part of the State-level Child Find effort.

According to the survey, States also disseminate materials to physicians and pediatricians. A few States also mention nurses, therapists, and other personnel in their efforts. Some States have personnel that work in the NICU with the nurses and family members to inform them about early intervention services. A Child Find representative attends discharge rounds in one State, and in another, the birth registry follows eligible infants and provides the necessary information related to early intervention and the referral process. These findings are consistent with Berman and Melner's (1992) recommendation that it is important to build relationships with other personnel who provide care to children including nurses and therapists, in efforts to promote early intervention to the medical community. Other State efforts include mailings, flyers, and brochures sent to doctors' offices, hospitals, NICUs , PICUs, and health clinics, according to the surveys. These findings are similar to those of Buck et al. (2000), Berman and Melner (1992), and *The Survey of Connecticut Pediatricians* (1997) who all reported that this is the manner in which pediatricians prefer to receive information about early intervention. Outreach efforts, participation in symposiums, presentations, exhibits at medical conferences, and participation in bi-weekly pediatric rounds were all mentioned in the surveys as ways that States promote Child Find to the medical community. Moreover, Michigan's public awareness plan outlines medically-related trade shows, conventions, and conferences as avenues for Child Find promotion. The public awareness plans from Michigan and Idaho reveal that radio and television ads are also used to promote Child Find.

Other efforts to promote Child Find to the medical community are done through collaboration. Although only 15% of the survey respondents reported their State has an interagency agreement with the medical community, 85% reported having a member of the medical community on their State ICC. Sixty percent of the survey respondents indicated their State ensures the NICU personnel inform parents of premature infants about early intervention. This is done through a variety of different approaches which is advantageous since Berman and Melner (1992) report that a singular approach to promoting Child Find and early intervention is not effective.

Overall, it appears that the States are making an effort to promote early intervention to the medical community, and are doing so using a variety of approaches. Although the majority of the State policies contain little if any mention of Child Find efforts, the public awareness plans, and results from the survey research provide detailed information about State efforts. However, the resources, personnel, time, and funding used to conduct these efforts are not being monitored effectively.

Question 2: How are Part C lead agencies evaluating the effectiveness of these public awareness campaigns?

To answer the second research question, I analyzed the fifth variable in the policy and public awareness plan as well as responses to the survey. The findings from all sources of data reveal that, for the most part, the States are not evaluating their Child Find efforts. According to the results of the policy analysis, States are doing little if any monitoring of their Child Find and public awareness efforts. In fact, only 10 State policies contained any mention of evaluation efforts. This is consistent with Berman and Melner's (1992) findings that States had little information on their monitoring efforts. The monitoring and evaluation efforts that were mentioned were vague and unclear, with the exception of Missouri. Missouri's policy detailed clear monitoring efforts. In their monitoring efforts, each LEA in Missouri aggregates their census data and reports to the State Department of Elementary and Secondary Education. The State Department then makes decisions about the Child Find efforts.

Relying on the policy analysis alone, it appears that the majority of States do not monitor the effectiveness of their Child Find efforts. However, the results from the public awareness plan analysis reveal that more States do, in fact, monitor. Although the number of plans received was low, and no generalizations can be made, it is interesting to note that three of the six plans contained information on monitoring efforts. The public awareness plans from Connecticut and Idaho both contained clear information related to monitoring efforts.

Connecticut's public awareness plan contained information on how the early intervention team reviews referral data from physicians for annual trends. Idaho's plan also contained information on collaborative meetings and a public awareness material review to monitor their Child Find efforts. Moreover, the survey reveals that 53% (n=17) of the States routinely collaborate with their local coordinators on the effectiveness of their State public awareness plan. Thirty-one percent (n=10) occasionally collaborate. Of the States that do collaborate, 59% do so through monitoring efforts, 47% use routine meetings, 32% make evaluation of the public awareness plan part of the State ICC agenda, and 56% use reports to monitor the public awareness plan.

A few respondents provided additional information and reported that their States use data system monitoring, and weekly pediatric meetings following rounds at the medical center. One respondent indicated that his/her state surveys the LEAs annually on what they need related to Child Find and public awareness items. Through these monitoring efforts, the States can locate areas that need further improvement, and areas that are effective, in addition to identifying barriers in their efforts to promote Child Find.

A number of questions on the survey were related to how and if States collect data on referral sources. All of the survey respondents reported that their State collects data on referral sources. Fifty-six percent collect data on the number of referrals from NICUs and 94% collect data on the number of referrals from the medical community in general. These results provide interesting information, although it would have been useful to have asked the respondents if their State uses their referral data to monitor the effectiveness of their Child Find efforts.

Question 3: What are the current barriers to promoting early intervention to the medical community?

Two survey questions addressed the third research question. The respondents described a number of barriers to promoting early intervention to the medical community. Sixty-five percent reported lack of time; 62% reported staffing issues; and 59% reported access to the medical community as barriers to promoting early intervention. It is interesting to note that the top two barriers are not related to the medical community at all, but are issues within the early intervention system. If there is not enough time and not enough personnel then Child Find efforts to the medical community will be limited no matter how detailed and comprehensive the efforts may be. One respondent explained that in his/her State the new CAPTA legislation has resulted in an overwhelmingly large volume of early intervention referrals which has taken time away from promoting Child Find to the medical community.

A few respondents indicated that there appears to be a general lack of understanding in the medical community that children need developmental services in addition to medical care. Another respondent indicated that when families report suspected delays to the pediatrician, the pediatrician continues to take the "wait and see" approach. Promoting collaboration was added as a possible solution to this dilemma. Scott et al. (1993) and Helm and Shishmanian (1997) also indicate that pediatricians do not make referrals to early intervention because they are uncertain of the efficacy of the program.

The survey respondents also provided useful information related to what assistance their State would require in order to effectively implement the new component in IDEA related to premature infants. Of those who responded to this question, the overwhelming majority requested information about how to access the medical community, and about successful models of what other States are doing to promote Child Find and early intervention to the medical community. Respondents also wanted to know what was being done at the national level; and information on the collaboration efforts between the AAP and Part C. Only one respondent felt that more training during medical school / pediatric residency would be useful.

Limitations

There are a number of limitations to the findings from this research. First, results are limited to the continental United States. Although efforts were made to include the US territories, those attempts were unsuccessful. As indicated earlier, only one US territory submitted the questionnaire. Second, I conducted the policy analysis using State-level policies only. Since the majority of the States indicated that Child Find efforts are the responsibility of the local districts, limited information was available at the State level. Every State except three (Hawaii, Missouri, and South Carolina) make Child Find and public awareness activities the responsibility of the local education agencies. Local level documents would therefore help us to better understand the public awareness activities. Third, the low response rate from the survey limits the generalizability of the findings. Even though I made systematic efforts to contact the coordinators and to receive the questionnaires, 33 of the 51 states (65%) and one of the five US territories (20%) responded to the survey.

The public awareness plan component of this study produced some interesting information related to state-level Child Find efforts; however after repeated attempts, only six plans were received. This is another limitation to the study.

The extant research on Child Find policy analysis is limited, and therefore, there was no research to use as a framework for my analysis. I based the rubric that I used on Caron's (2003) research related to newborn hearing screening State policies.

Recommendations for Future Research

There are a number of areas for future research. First, it would be helpful to obtain more state public awareness plans and analyze them for evidence of objectives, timelines and methods of evaluation. My findings show that the public awareness plans have more detailed information related to State-level Child Find efforts when compared to the State policies. Second, the majority of States make Child Find the responsibility of LEAs. It would be interesting to survey LEAs about their public awareness / Child Find efforts. An analysis of the local policies related to Child Find could also provide a wealth of data about what the local districts do to reach out to the medical community to promote early intervention. A survey of the ICC and the LICC (Local Interagency Coordinating Council) chairs might also provide data about interagency agreements and collaboration with the medical community at the State and local levels. A case study of a few LICC members and an analysis of the LICC meeting notes would also add to the understanding of Child Find at the local levels. Also, if the LEAs have local public awareness plans, this information would be beneficial to obtain and analyze.

On a national level, future research could investigate the State Improvement Plans, and the monitoring efforts of the federal government. Each State is required to report to the federal government on the implementation of their Child Find program. An analysis of these reports might provide additional information about Child Find.

Four of the five states with the most detailed Child Find / public awareness policies, have Education as their lead (or co-lead) agency governing Part C services. Of the 51 states (including the District of Columbia), 12 have Education as the Part C lead agency. This is an interesting finding and warrants further research. The education community may have different ideas, priorities, and resources related to early intervention in general, and may recognize the need for more developed, detailed, and clear policies related to Child Find.

Implications for Practice

When asked if there was any information the respondents needed in order to improve their Child Find and public awareness efforts to the medical community, a common theme emerged. We need an effective model. One model might be for the educational community to partner with the medical community at the federal level and approach Child Find in a collaborative way.

According to the transactional model, efforts will not be successful if changes are made only at one level. Corollary changes on additional and influential levels must occur to enhance the existing competencies of the child and family (Sameroff & Fiese, 2000). For example, in the more distant interactions, variables, investigated in this study, must also be addressed to make sure the medical community is informed about the efficacy of early intervention and equipped with appropriate and valid information to provide to the families**.** The Child Find efforts at the state or local levels must appropriately address what the medical community needs in order to promote early intervention effectively to the families. At another distal interactional level, if the medical community needs information on eligibility criteria or the benefits of early intervention, the Child Find efforts should include this information, in whatever mode of communication is successful for that particular community. The State needs to provide the resources and funding to allow the local Child Find efforts to be promoted and conducted successfully and on an on-going basis. Moreover, the LEAs need to communicate this need to the state.

Sameroff and Fiese (2000) explain that program efficacy depends on sound implementation. A potentially effective model of public awareness cannot be expected to demonstrate positive effects if it is not delivered effectively and monitored appropriately.

In addition to the monitoring efforts from the federal government to make sure the States are doing what they report they do, monitoring efforts should also exist within each State.

However, even if there is a detailed public awareness plan, and an effective Child Find model to work with the medical community, limited staff and funding could be a major barrier. This study began with the statement that early intervention is not uniformly supported and is not entirely embraced (Meisels and Shonkoff, 2000). The findings of this research support this statement, on behalf of both the fields of Education and Medicine.

Meisels and Shonkoff (2000) explain that the major question facing the field of early intervention is not whether young children are worthy of public investment, but how to capitalize on current knowledge and mobilize our collective resources to ensure a better developmental outcome for our children. However, without sound financial investment in our children, no matter whom we blame, we are depriving them of the services they are entitled to receive.

Summary and Conclusions

The principal findings from the policy analysis reveal that the overwhelming majority of states have vague or ambiguous objectives related to Child Find and public awareness activities directed toward the medical community. The majority of States make Child Find activities a responsibility of the LEAs. Although it may be most appropriate for local entities to have the responsibility for reaching the medical community in their area, it is the responsibility of the State to ensure that these activities occur.

Although the new component in the IDEA reauthorization concerning a special focus on families of premature infants was only added one and a half years ago, the medical community has always been considered a primary referral source; however only four states mentioned them in their state policies. No statement was found in any State policy related to public awareness and NICU personnel.

Further, only 11 States have provisions in their policies to monitor the effectiveness of their public awareness efforts. Of these 11, 10 are rather vague in their monitoring efforts and statements. A State can have a very clear and well-developed public awareness policy, however if there are no measures taken to evaluate whether the campaign is reaching the desired population and conveying the desired message, the ultimate goal of increasing referrals will not happen. Program efficacy depends on sound implementation (Meisels & Shonkoff, 2000).

Although it is not a requirement for States to have a public awareness plan in order to receive federal funding, 70% of the survey respondents reported their State had a plan. Of those respondents who reported having a plan, 64% indicated they have specific guidelines related to promoting early intervention to NICU personnel.

Although I analyzed only six plans, they provided important additional information about State-level public awareness efforts. The overall objectives were much more detailed and clear as were the types of public awareness efforts to be conducted, and materials to be distributed. The plans contained more comprehensive information related to targeting the medical community and procedures for doing so.

This finding is not surprising. State policies are comprehensive and must cover all aspects of early intervention, as well as special education. When looking through the policies, many state policies had very lengthy sections on due process. With all that a State policy is required to contain in order to receive federal funding, it is not surprising that the more ‘user friendly’ public awareness plan contained more relevant information related to Child Find efforts, and was written in a more understandable manner.

The results of the survey revealed that States are promoting early intervention and Child Find to the medical community and NICU personnel. The majority of States make public awareness efforts the responsibility of all personnel working in the early intervention system. Collaboration efforts are also happening in the States with 85% of the State ICCs having a representative from the medical community. Most states collect data referral sources, including NICUs and medical-related institutions. Public awareness plans seem to be prevalent in most States, and include information on the medical community. However, despite all these efforts on behalf of the States, barriers, including staffing, personnel, funding, and access to the medical community all impact how early intervention and Child Find is promoted to the medical community.

Appendices

Appendix A: Part C Lead Agencies

State	Lead Agency
Alabama	Rehabilitation Services
Alaska	Health and Social Services
American Samoa	Health
Arizona	Economic Security
Arkansas	Human Services/Developmental Disabilities
California	Developmental Services
Colorado	Human Services/Developmental Disabilities
Commonwealth of Northern Mariana Islands	Education
Connecticut	Mental Retardation
Delaware	Health and Social Services
District of Columbia	Human Services
Florida	Health (Children's Medical Services)
Georgia	Human Resources/Division of Public Health
Guam	Education
Hawaii	Health
Idaho	Health & Welfare/Developmental Disabilities
Illinois	Human services
Indiana	Family and Social Services
Iowa	Education

Kansas	Health and Environment
Kentucky	Health Services
Louisiana	Health & Hospitals
Maine	Education
Maryland	Education
Massachusetts	Public Health
Michigan	Education
Minnesota	Education
Mississippi	Health
Missouri	Education
Montana	Public Health and Human Services
Nebraska	Education and Health & Human Services (co-lead)
Nevada	Human Resources/Health
New Hampshire	Health and Human Services
New Jersey	Health and Senior Services
New Mexico	Health
New York	Health
North Carolina	Health and Human Services
North Dakota	Human Services
Ohio	Health
Oklahoma	Education
Oregon	Education

Pennsylvania	Public Welfare
Puerto Rico	Health
Rhode Island	Human Services
South Carolina	Health and Environmental Control
South Dakota	Education
Tennessee	Education
Texas	Assistive and Rehabilitative Services
Utah	Health
Vermont	Education and Human Services (co-lead)
Virgin Islands	Health
Virginia	Mental Health, Mental Retardation & Substance Abuse Services
Washington	Social and Health Services
West Virginia	Health and Human Resources
Wisconsin	Health and Family Services
Wyoming	Health

Appendix B: Scoring Protocol

Variable 1: Clearly stated short term objectives as they relate to targeting medical personnel who work with infants born prematurely and their families

0 = No stated short term objective related to public awareness efforts

1 = Vague or ambiguously worded objectives (e.g. an objective that is not possible to measure) that does <u>not</u> mention efforts targeting medical personnel who work with infants born prematurely and/or their families

1.5 = Vague or ambiguously worded objectives (e.g. an objective that is not possible to measure) that <u>does</u> mention efforts targeting medical personnel who work with infants born prematurely and/or their families

2 = Clear and concise appropriate short term objectives that <u>do not</u> mention targeting medical personnel who work with infants born prematurely and/or their families

2.5 = Clear and concise appropriate short term objectives that <u>do</u> mention targeting medical personnel who work with infants born prematurely and/or their families

Variable 2: Types of public awareness materials/efforts that will be done to educate the medical personnel who work with infants born prematurely and their families

0 = No mention of public awareness materials (e.g. brochures, handouts, posters) or efforts (e.g. presentation at grand rounds or AAP chapter meetings) at all in the policy

1 = Vague mention of public awareness materials/efforts with little or no information provided that does <u>not</u> mention efforts targeting medical personnel who work with infants born prematurely and/or their families

1.5 = Vague mention of public awareness materials/efforts with little or no information provided that <u>does</u> mention efforts targeting medical personnel who work with infants born prematurely and/or their families

2 = Clear and detailed information related to what materials will be developed and/or disseminated that <u>do not</u> specifically target medical personnel who work with infants born prematurely and/or their families

2.5 = Clear and detailed information related to what materials will be developed and/or disseminated that <u>do</u> specifically target medical personnel who work with infants born prematurely and/or their families

* Screening efforts do not count as a type of public awareness effort

Variable 3: Description of who the information will be disseminated to, related to the medical personnel who work with infants born prematurely and/or their families

0 = No description of who the intended recipients are who will receive the public awareness materials

1 = Minimal description of who the recipients are (e.g. parents, social workers, etc.) without mention of medical personnel who work with infants born prematurely and/or their families
* Includes the words "general public" only

1.5 = Minimal description of who the recipients are (e.g. nurses, pediatricians etc.) with little mention of medical personnel who work with infants born prematurely and/or their families

2 = Clear description of who the information will be disseminated to without mention of medical personnel who work with infants born prematurely and/or their families

2.5 = Clear description of who the information will be disseminated to (e.g., neonatal nurse practitioners, medical students, medical residents, neonatology fellows, neonatology attendings, etc.) related to medical personnel who work with infants born prematurely and/or their families

Variable 4: The timeline for dissemination of materials/efforts related to medical personnel who work with infants born prematurely and/or their families

0 = No timeline provided for dissemination of materials/efforts

1 = Vague timeline provided (e.g. within the year) without mention of medical personnel who work with infants born prematurely and/or their families
* Includes the words "annual" only

1.5 = Vague timeline provided (e.g. within the year) with mention of medical personnel who work with infants born prematurely and/or their families

2 = Clear description for the dissemination of the materials and public awareness efforts (e.g., on a month-to-month basis, by the end of the year, etc.) without mention of medical personnel who work with infants born prematurely and/or their families
* Includes if a specific date is provided

2.5 = Clear description for the dissemination of the materials and public awareness efforts (e.g., on a month-to-month basis, by the end of the year, during the first semester of residency, etc.) with mention of medical personnel who work with infants born prematurely and/or their families

Variable 5: Information on short term objective evaluation related to medical personnel who work with infants born prematurely and/or their families

0 = No information on an evaluation of objectives

1 = Ambiguous or vague description of evaluation efforts (e.g., simply stating that they will evaluate their efforts but not providing any means to how the evaluation will occur and how they will alter their efforts) without mention of medical personnel who work with infants born prematurely and/or their families
* Includes if there is mention of a specific person who is accountable for child find activities

1.5 = Ambiguous or vague description of evaluation efforts (e.g., simply stating that they will evaluate their efforts but not providing any means to how the evaluation will occur and how they will alter their efforts) with mention of medical personnel who work with infants born prematurely and/or their families

2 = Clear evaluation measures provided (e.g., evaluations based on where referrals come from, questionnaires sent to primary referral sources) without mention of medical personnel who work with infants born prematurely and/or their families

2.5 = Clear evaluation measures provided (e.g., evaluations based on where referrals come from, questionnaires sent to primary referral sources) with mention of medical personnel who work with infants born prematurely and/or their families

* No score for information on short term objective evaluation if the only mention is data evaluation for discrimination or disproportionate representation of minority students

Appendix C

Inter-Rater Reliability Coding Scores

State	First Coder Score	Second Coder Score	Final Score
Alabama	1	1	1
District of Columbia	1	1	1
Idaho	6	7	7
Kansas	5	4	4
Louisiana	5	4	4
Minnesota	1	1	1
Montana	2	1	1
New Jersey	4	2	2
North Carolina	3	2	2
Ohio	4	4	4
Rhode Island	2	2	2
Utah	3	2	2
Washington	3	4	4

Appendix D: Consent Form for Pilot Study

Consent Form

Project Title: Investigation of State-Level Public Awareness Campaigns to Promote Early Intervention to the Medical Community

Why is this research being done?

This is a research project being conducted by Jody Lynn Fulton a doctoral student in early childhood special education at the University of Maryland, College Park. The research is under the supervision of Dr. Joan Lieber. We are inviting you to participate in this research project because you, as the local Part C coordinator have direct knowledge of your jurisdiction's public awareness campaigns to promote early intervention to the medical community. Research indicates that many medical personnel, including pediatricians, are unaware of early intervention and therefore not communicating to families the importance and availability of these services. We would like to better understand effective practices in this area, as well as barriers that prohibit the provision of these services. The purpose of this research project is to survey each state and US territory on their practices to promote early intervention to the medical community. However, before this survey will be sent to the state and territory coordinators, we would like to pilot test the survey with the local Part C coordinators in Maryland.

What will I be asked to do?

The procedures involve completing a 30 question survey. The survey contains mainly yes/no questions, and some questions with response categories. There is one open-ended question at the end and there will be space for you to further explain your answers if needed. The questions ask you about what your area does to promote early intervention to the medical community. Examples of the survey questions include: Do you have a general public awareness plan? Do you collect data on the number of referrals from the neonatal intensive care units (NICUs)?

You will first receive an initial phone call in which we will explain the purpose of the research, and invite you to participate. Upon your agreement to participate, the survey will be mailed to you along with a self addressed stamped envelope for you to return your completed survey to us. You will receive only one survey; no follow-up surveys are part of this research.

What about confidentiality?

We will do our best to keep your personal information confidential to the extent allowed by law. Your names will not be used in the write up of this research. Individual local jurisdiction results will not be reported either, rather the results will be reported in the aggregate to protect your confidentiality in participating in this study. We are the only people who will be collecting this data. Your responses will be stored on my personal computer in my home office, and a back up copy of your survey will also be stored in my home office in a secure and locked cabinet. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks from participating in this research study.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about public awareness campaigns to promote early intervention to the medical community. We hope that, in the future, other people might benefit from this study through improved understanding of effective practices for educating the medical community on the importance and availability of early intervention services.

Do I have to be in this research? May I stop participating at any time?

Your participation in this research is completely voluntary. You can choose to not answer any question that makes you feel uncomfortable. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Ms. Jody Lynn Fulton, under the supervision of Dr. Joan Lieber, professor of early childhood special education at the University of Maryland, College Park. If you have any questions about the research study itself, please contact me at (410) 918-0931 or jlfulton@comcast.net. Or, you may contact my advisor Dr. Joan Lieber, at (301) 405-6467 or jlieber@umd.edu. If you have questions about your rights as a research subject, please contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678. This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

Statement of Consent

In signing this form, I give my consent to participate in this research.

______________________________________ __________________

Signature Date

Appendix E: Consent From for State-Level Survey

Consent Form

Project Title: Investigation of State-Level Public Awareness Campaigns to Promote Early Intervention to the Medical Community

Why is this research being done?

This is a research project being conducted by Jody Lynn Fulton a doctoral student in early childhood special education at the University of Maryland, College Park. The research is under the supervision of Dr. Joan Lieber. We are inviting you to participate in this research project because you, as state Part C coordinator, have direct knowledge of your state's or territory's public awareness campaigns to promote early intervention to the medical community. Research indicates that many medical personnel, including pediatricians, are unaware of early intervention and therefore not communicating to families the importance and availability of these services. The purpose of this research project is to survey each state and US territory on their practices to promote early intervention to the medical community. We would like to better understand effective practices in this area, as well as barriers that prohibit the provision of these services.

What will I be asked to do?

The procedures involve completing a 30 question survey. The survey contains mainly yes/no questions, and some questions with response categories. There is one open-ended question at the end and there will be space for you to further explain your answers if needed. The questions ask you about what your state or territory does to promote early intervention to the medical community. Examples of the survey questions include: Do you have a general public awareness plan? Do you collect data on the number of referrals from the neonatal intensive care units (NICUs)?

The survey will be sent to you via email in which you will be given a link to a web-based survey. Your consent to participate will be assumed upon your completion of the web-based survey. You will receive only one survey; no follow-up surveys are part of this research.

What about confidentiality?

We will do our best to keep your personal information confidential to the extent allowed by law. Your names will not be used in the write up of this research. Individual state's results will not be reported either, rather the results will be reported in the aggregate to protect your confidentiality in participating in this study. We are the only people who will be collecting this data. Your responses will be stored on my personal computer in my home office, and a back up copy of your survey will also be stored in my home office in a secure and locked cabinet. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks from participating in this research study.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about your state's or territory's public awareness campaigns to promote early intervention to the medical community. We hope that, in the future, other people might benefit from this study through improved understanding of effective practices for educating the medical community on the importance and availability of early intervention services.

Do I have to be in this research? May I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. You can choose not to answer any questions that make you feel uncomfortable. If you decide to participate in this research, you may stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Ms. Jody Lynn Fulton, under the supervision of Dr. Joan Lieber, professor of early childhood special education at the University of Maryland, College Park. If you have any questions about the research study itself, please contact me at (410) 918-0931 or jlfulton@comcast.net. Or, you may contact my advisor Dr. Joan Lieber, at (301) 405-6467 or jlieber@umd.edu. If you have questions about your rights as a research subject, please contact: Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-0678. This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.

Statement of Consent

If you complete and return the survey, you have agreed to participate in the study. I would like to thank you again for taking the time to participate in this survey.

Appendix F: Web-Based Questionnaire

Early Intervention Awareness STATE

Directions: **Please complete the questionnaire by either choosing the appropriate response category by clicking on the space provided, or by using the text boxes to type in your response. At the completion of the survey, please click on 'Submit'.**

GeneralInformation. Please indicate which state you are representing.

☐

I. Background / Demographic Information

1. How long have you been in your current position as Part C coordinator? (check one)

☐ less then 6 months

☐ 6 months to one year

☐ 1 to 5 years

☐ greater then 5 years

2. How many full time employees (FTE) do you have working in your early intervention program?

# of FTE ☐

3. Do you have any staff members whose responsibility includes public awareness activities?

☐ Yes

☐ No

4. If you answered Yes to question 3, please indicate how many staff members.

# of Staff Members ☐

5. Do you have any staff members whose responsibility includes promoting public awareness to the medical community?

☐ Yes

☐ No

6. If you answered Yes to question 5, please indicate how many staff members.

\# of staff members ☐

7. Please list your criteria for automatic eligibility into the early intervention program under the high probability / conditions of established risk category (e.g. birth weight <1200grams).

II. State Interagency Coordinating Council (ICC) Information

8. Please indicate the number of local Part C coordinators do you have in your state?

No. ☐

9. Does your state have a written interagency agreement with the medical community?

○ Yes

○ No

10. If you answered yes to Question 9, is there a component in the interagency agreement related to public awareness to the medical community?

○ Yes

○ No

11. Do any personnel representing the medical community serve on your state Part C ICC?

○ Yes

○ No

12. If you answered Yes to Question 11, please indicate the title(s) of the person(s) who serve(s) on your state Part C ICC?

13. To what extent do you collaborate with your local Part C coordinators to evaluate the effectiveness of your state public awareness plan?

○ Routine collaboration

○ Occasional collaboration

○ Rare collaboration

○ No collaboration

○ Unsure

14. If you collaborate with your local Part C coordinators to evaluate the effectiveness of your state public awareness plan, how do you do so? Please check all that apply and explain your response in the space provided below.

☐ Routine meetings

☐ Monitoring efforts

☐ Part of state or territory ICC agenda

☐ Reports

☐ Other (please explain)

Other. Please Explain:

III. Referral Information

15. Does your state collect data on how many early intervention referrals you receive each year?

○ Yes

○ No (if you answer 'no', please proceed to question 22)

16. If you answered Yes to Question 15, please indicate how many referrals to early intervention that you receive each year.

# of referrals

17. Does your state collect data on where the referrals come from?

☐ Yes

☐ No

18. Does your state collect data on the number of referrals from the neonatal intensive care units (NICUs)?

☐ Yes

☐ No

19. Does your state collect data on the number of referrals from medical related institutions (e.g., hospitals, medical centers, pediatrician's offices)?

☐ Yes

☐ No

20. Please indicate the total number of early intervention referrals received for the 2004 fiscal year.

2004 ☐

21. Please list the various sources for which early intervention referrals were received and the number of referrals received from each source in 2004.

IV. Public Awareness Information

22. Does your state have a general public awareness plan?

☐ Yes

☐ No (If you answered 'No' please proceed to Question 29)

23. Are there specific guidelines in your public awareness plan to promote early intervention to the following (please check all that apply):

	Yes	**No**
NICU Personnel	☐	☐
Pediatricians	☐	☐
Family Physicians	☐	☐
General Medical Community	☐	☐

	Yes	**No**
Other Specialists	☐	☐

24. Please indicate the titles of the persons who develop your state public awareness plan?

25. In the last year, did your state provide any public awareness activities that targeted the medical community?

○ Yes (please explain below)

○ No

PleaseExplain.

V. Information Related to the Medical Community

26. Does your state ensure that NICU personnel inform parents of the Part C early intervention program?

○ Yes

○ No

27. If you answered Yes to Question 27, please explain how you determine the extent to which this information is made available to parents through primary referral sources?

VI. Other Information

28. Does your state have a birth defects registry?

○ Yes

○ No

○ Unsure

29. Which, if any, of the following do you see as a current barrier to promoting early intervention to the medical community? (Please check all that apply and feel free to explain your answers in the space provided below).

☐ There are no current barriers

☐ Funding/Financial issues

☐ Training issues

☐ Lack of time

☐ Staffing issues

☐ Access to the medical community

☐ Other (please explain below)

OtherPleaseExplain.

30. What assistance would be beneficial for you in implementing the new clause in IDEA 2004 requiring states and territories to target public awareness activities to medical personnel who work with premature infants and their families (e.g., information on ways to access the medical community)?

Thank you for taking the time to complete this survey.

Submit Survey

Powered by SurveySolutions: Conduct your own online surveys

Appendix G: Initial Letters Mailed to Part C Coordinators

February 1, 2006

(Coordinator's Name),

My name is Jody Lynn Fulton and I am a doctoral student studying early childhood special education at the University of Maryland, College Park. I am conducting a national survey under the supervision of my advisor, Dr. Joan Lieber, to investigate what each state and US territory is doing to promote early intervention to medical primary referral sources.

As you know, the Individuals with Disabilities Education Act (IDEA) was recently reauthorized in 2004. This new reauthorization brought about many changes in the law. One of these changes specifically requires states to educate medical personnel who provide services to premature infants and their families, on the importance and availability of early intervention services. Research indicates that many medical personnel that have direct contact with families of young children, including pediatricians, are unaware of early intervention and therefore not able to educate families on the availability and importance of these services. With your participation in this survey, we are hoping to better understand effective practices in this area, as well as barriers that prohibit the provision of these services.

Please expect to receive a survey via email regarding (state)'s early intervention public awareness campaigns. The survey will be sent on **Monday February 13, 2006**, and should take approximately (20) minutes to complete. If you would prefer, I can send you a paper copy of the questionnaire for you to fill out and return. You also may choose to complete the survey over the phone. If you choose either of these options, please contact me either by phone or by email, and I will make the necessary arrangements to accommodate your request. Should you have further questions regarding your participation in the survey, please feel free to contact me by phone (410-918-0931) or email (jlfulton@comcast.net). You may also contact my advisor at jlieber@umd.edu. I am looking forward to learning about (state)'s early intervention public awareness programs.

Sincerely,

Jody Lynn Fulton
Doctoral Student

Appendix H: Emails Sent to Coordinators February 13th with Link to Web-based Questionnaire

Dear (Part C Coordinator),

I hope you are doing well and that you received my letter regarding the research I am conducting for my dissertation. I am investigating what the individual states are doing to promote early intervention to the medical community. I am hoping to better understand best practices that enhance the provision of early intervention services as well as any barriers that prohibit the provision of these services.

Please take the time to complete the survey. I have provided the link below. If you have any questions regarding my research or the survey please do not hesitate to contact me either by phone (410 918-0931) or by email: jlfulton@comcast.net. I would be delighted to answer any questions or make any necessary accommodations to assist you in completing the survey. I am really looking forward to learning more about (state)'s early intervention public awareness efforts to the medical community!

Survey link: http://express.perseus.com/perseus/surveys/1734848031/38d001.htm

Sincerely, Jody Lynn Fulton

Appendix I: Email Sent to Part C Coordinators on February 24th

Hi (Part C Coordinator)!

I left you a voice mail earlier today (Friday Feb. 24) regarding the public awareness survey. I am sorry I was not able to speak with you. I am following up with the states I have not heard back from to see if there is anything I can do to assist you in completing the survey.

I have attached the link to the survey if that is most convenient for you. Please let me know if there is someone else in your office who would be able to complete the survey & I would be delighted to contact that person. If you would like to complete the survey over the phone or if you would prefer to receive the survey via postal mail, please let me know & I will make those accommodations for you.

We are trying to receive as many responses as possible in order to derive any meaningful conclusions from the data, so please let me know if there is anything I can do to assist you! The survey link is below & I look forward to hearing from you!

Thank you, Jody

http://express.perseus.com/perseus/surveys/1734848031/38d001.htm

Appendix J: Email Sent to Part C Coordinators on March 7th

Hi (Coordinator),
I just left you a voice mail earlier today regarding the public awareness survey I am conducting for my dissertation at the University of Maryland. I am following up with the states I have not heard back from to see if there is anything I can do to help you complete the survey.

I realize you are a very busy person, so if there is someone else in your office who you would rather I correspond with regarding a response for (state), I would be delighted to contact that person. Please just let me know.

I have attached another link to the survey for your convenience. Please let me know if you have any questions or if there is anything I can do to assist you.

Survey Link: http://express.perseus.com/perseus/surveys/1734848031/38d001.htm

Thank you, Jody Lynn Fulton
Phone (410-918-0931)
Email (jlfulton@comcast.net)

Appendix K: Letter Sent to Part C Coordinator on March 15th

March 15, 2006

Dear (Coordinator),

My name is Jody Lynn Fulton and I am the doctoral student at the University of Maryland who has been contacting you via email regarding a public awareness survey I am conducting for my dissertation. I respect the fact that you are an extremely busy person, and I thought it might be more convenient for you to receive a copy of the survey through the postal mail.

In addition to the survey, I have enclosed the IRB consent form for your review and a self-addressed stamped envelope for you to return the survey. If it is easier for you to complete the survey on-line, please visit the following website for a direct link to the survey: http://express.perseus.com/perseus/surveys/1734848031/38d001.htm.

I am trying to receive as many surveys from the states as possible in order to derive any meaningful conclusions from the data. If there is someone in your office who would be able to fill out the survey, please feel free to pass it along and I would be delighted to correspond with that individual instead.

In addition to the survey, I am asking that if (state) has a general public awareness plan, please either enclose a copy of the plan or please email me a copy (jlfulton@comcast.net). If you could complete and return the survey by March 31, 2006, I would greatly appreciate it, as I am hoping to defend my dissertation this spring.

If you have any questions, or if I can be of assistance to you in completing the survey in any way, please contact me either by phone (410-918-0931) or email: jlfulton@comcast.net. Thank you again for your time.

Sincerely,

Jody Lynn Fulton
Doctoral Student

Appendix L: Final email to the coordinators

Hi (coordinator),
I am sorry I was never able to speak with you, but I did leave a voice mail earlier today regarding the public awareness survey from the University of Maryland. I sent a copy of the survey in the mail on March 15th, and I was just following up to see if you had any questions regarding the survey.

I have also provided you with a link to the on-line version of the survey if it is easier for you to complete the survey this way:
http://express.perseus.com/perseus/surveys/1734848031/38d001.htm

If you could complete either the survey sent in the mail or the on-line version by the end of this week / early next week, I would greatly appreciate it. I am ending data collection, so I will no longer be bothering you! Thank you in advance for your time & patience with me in my attempts to learn more about (state)'s early intervention public awareness efforts! Have a wonderful week!

Sincerely,
Jody Lynn Fulton
410-918-0931

Appendix M: State Policy Scoring Results

State Policy Scoring Results

State	Variable One-Objective	Variable Two-Materials & Objectives	Variable Three-Dissemination	Variable Four-Timeline	Variable Five-Evaluation	Total
Alabama	1	0	0	0	0	1
Alaska	1	1	1	0	0	3
Arkansas	2	1	1	0	0	4
Arizona	1	1	1	0	0	3
California	0	0	0	0	0	0
Colorado	2	1	0	0	1	4
Connecticut	1	0	0	0	0	1
District of Columbia	1	0	0	0	0	1
Delaware	1	1	0	0	0	2
Florida	0	0	0	0	0	0
Georgia	1	0	0	0	0	1
Hawaii’s	1	0	0	0	0	1
Iowa	1	0	0	0	0	1
Idaho	1	2	1	2	1	7
Illinois	2	0	0	0	0	2
Indiana	1	2	1	0	0	4
Kansas	1	1	1	1	0	4
Kentucky	0	0	0	0	0	0
Louisiana	1	1	1	0	1	4
Massachusetts	0	0	0	0	0	0
Maryland	1	1	0	0	0	2
Maine	2	0	0	0	0	2
Michigan	0	0	0	0	0	0
Minnesota	1	0	0	0	0	1
Missouri	2.5	2	2	2	2	10.5
Mississippi	0	0	0	0	0	0
Montana	1	0	0	0	0	1
North Carolina	1	0	0	0	1	2
North Dakota	0	0	0	0	0	0
Nebraska	1	0	0	0	0	1
Nevada	1	1	0	0	0	2
New Hampshire	2.5	1.5	1.5	1	0	6.5
New Jersey	1	0	0	0	1	2
New Mexico	1	0	0	0	0	1
New York	0	0	0	0	0	0
Ohio	1	2	1	0	0	4
Oklahoma	2	2.5	1	1	0	6.5

Oregon	2	0	0	1	0	3
Pennsylvania	1	1	1	1	0	4
Rhode Island	1	0	0	0	1	2
South Carolina	1	0	0	0	1	2
South Dakota	2.5	0	2.5	0	1	6
Tennessee	1	1	1	0	0	3
Texas	1	0	0	0	0	1
Utah	1	0	0	0	1	2
Virginia	1	1	1	1	1	5
Vermont	2	2	1	1	0	6
Washington	1	2	1	0	0	4
Wisconsin	0	0	0	0	0	0
West Virginia	1	0	1	1	0	3
Wyoming	1	0	0	0	0	1

Appendix N: Side-by-Side Analysis of State Policies and Public Awareness Plans as they Relate to Child Find Efforts and the Medical Community

State: Connecticut

Policy Score	Plan Score	Variable
1	2.5	1: Clearly stated short term objectives
0	2.5	2: Types of public awareness materials/efforts
0	2.5	3: Who the information will be disseminated to
0	2.5	4: Timeline
0	2.5	5: Information on evaluation
Total 1	12.5	

State: Florida

Policy Score	Plan Score	Variable
0	2.5	1: Clearly stated short term objectives
0	2.5	2: Types of public awareness materials/efforts
0	2.5	3: Who the information will be disseminated to
0	2.5	4: Timeline
0	0	5: Information on evaluation
Total 0	10	

State: Idaho

Policy Score	Plan Score	Variable
1	2.5	1: Clearly stated short term objectives
2	2.5	2: Types of public awareness materials/efforts
1	2.5	3: Who the information will be disseminated to
2	2.5	4: Timeline
1	2.5	5: Information on evaluation
Total 7	12.5	

State: Michigan

Policy Score	Plan Score	Variable
0	1.5	1: Clearly stated short term objectives
0	2.5	2: Types of public awareness materials/efforts
0	2.5	3: Who the information will be disseminated to
0	2.5	4: Timeline
0	0	5: Information on evaluation
Total 0	9	

State: Texas

Policy Score	Plan Score	Variable
1	2.5	1: Clearly stated short term objectives
0	1.5	2: Types of public awareness materials/efforts
0	2.5	3: Who the information will be disseminated to
0	1.5	4: Timeline
0	0	5: Information on evaluation
Total 1	8	

State: Wyoming

Policy Score	Plan Score	Variable
1	2	1: Clearly stated short term objectives
0	2	2: Types of public awareness materials/efforts
0	2	3: Who the information will be disseminated to
0	1	4: Timeline
0	1	5: Information on evaluation
Total 1	8	

Appendix O: State ICC Members

Representatives from the Medical Community Serving on the State ICCs

Title	Number of States
Pediatrician from the state university	3
Physician Health District representative	
Division of Health representative	
Pediatrician	9
Neonatal nurse practioners (NNPs)	
Hospital representatives	
Director of Medicaid Managed Care	
Medical director of the pediatric residency program	
State AAP chapter member	
General physician	6
Instructor for Nurse Training Program	
Pediatric Association representative	
Developmental pediatrician	3
Developmental pediatrics medical director	
Representative from the Physician Community Health / Public Health Division	
Director of the Children’s Special Health Care Services	
Nurse	
Neonatologist	

Appendix P: Persons Who Develop State Public Awareness Plans

- Part C Regional Manager, Public Relations Firm
- Part C Child Find Coordinator, and Part B State Education Director
- Part C Coordinator and Contracted Program
- Co-Leads – Health and Human Services and Department of Education and Family Partners, and twenty-nine local planning region teams
- Public Awareness Coordinator
- Department of Human Services staff with review and approval from the State Part C ICC
- Educational Projects Coordinator, public health Part C planner, social services Part C planer, ICC workgroup
- Community Partnerships Specialist
- The Public Awareness Plan is not a separate document & is developed by the Part C agency and reviewed at public hearings
- Director Program Specialist Administrative Assistant
- Local Part C Coordinators
- 16 local sites and their local agencies, hospitals, etc.
- An adhoc workgroup that assists the lead agency in addressing public awareness plan. The State Performance Plan addresses public awareness and child find activities
- Public Awareness Coordinator in collaboration with other state staff and ICC

- Several state and the program planning committee of the statewide ICC
- Help from the providers and the ICC
- Professional Marketing Firm Contractor, early intervention experts, state ICC approval which includes parents and the State Department of Education Communication Office
- Early intervention specialist and the ICC public Awareness Subcommittee members which includes families, ICC members and providers
- State Child Find committee
- Part C Coordinator, program specialists, administrative supervisor
- Early Start State Services Unit Supervisor, contract staff with input from ICC's Public Awareness Committee, and local outreach from regional centers, LEAs, and Early Start Family Resource Centers.
- Sub committee of ICC and contractor with the State University and the staff of the Birth to Three program
- Pediatrician, social worker, early intervention staff

Appendix Q: Public Awareness Activities Targeting the Medical Community

- A flyer was specifically designed for families in the NICU. Procedures for working with families with children in the NICU were also developed. Providers begin working with the family in the hospital setting.
- Information is distributed in physician's packages
- Presentations; exhibits at conferences; contract with the state AAP and AFP to promote awareness, developmental screening, and referrals to early intervention
- Developmental Screening Symposium where physicians and others were trained regarding the use of developmental screening tools. Development of referral binders targeting primarily physicians/medical personnel to aid in educating referral sources about the benefits of early intervention and how to make the necessary referrals. The binder includes tips on how to discuss developmental concerns and the referral with the family. Physician education – a team of physicians is contracted to go around the state visiting other physicians in their offices to educate them about the benefits of early intervention and how to make referrals.
- Secured grants with medical institutions to identify and refer children who may be eligible for early intervention services.
- The development an educational program that targets parents, the medical community and other community agencies to encourage a developmental

screening to be completed on every child before they turn two-years of age. Posters, post cards, and radio advertisements are also a part of the activities.

- The Co-leads participate in medical community meetings and collaborate with low incidence groups such as vision, hearing loss and autism. Training is completed at the State University Medical Center and local Planning Region Teams also meet with their local physicians and hospitals on a regular basis.
- A letter was sent from the Department of Health to pediatricians with eligibility and referral information
- Collaboration exists with the State Chapter of the AAP to promote public awareness among its members. Local Child and Family Connections offices are required to participate in Child Find and public awareness in their area and disseminate information on referrals to the primary referral sources
- Materials are mailed to hospitals/NICUs/offices. Resource tables are also held at medical and nursing conferences. Collaboration with another state agency to complete primary care office visits, and meetings with the State AAP are held.
- A pocket guide and brochure are distributed to local medical providers.
- Developing a website to include Part C information and pediatric learning collaborative to discuss the use of screening tools.
- Packets of materials are given to physicians and presented to medical providers through a presentation format with local Part community members.
- The position is now vacant, and the respondent was unsure of the activities.
- Mailings to all licensed OB/GYNs

- Local programs target medical programs in their community
- Physician Training occurs with Child Development Resources.
- Collaboration with the Title V and Health Check program to disseminate eligibility and referral information to providers. Coordinated development of the Public Awareness plan with the Children Health Insurance Program (CHIP). This effort also includes the development of public education materials for families but it is distributed through the medical providers.
- Posters and brochures are distributed
- Occurs at the local levels.
- A HealthCare Professionals Outreach effort was completed which focused on physicians and residents from the State University in Pediatrics, Child Psychiatry and Family Practices. About eight sites each year do this for the last three years.
- Distribution of brochures with a cover letter from the chairperson of the state association of pediatrics is given to all pediatricians in the state endorsing early intervention and referrals. The Part C Coordinator serves on the state Perinatal Advisory Committee and attends quarterly meetings. The local early intervention staff also serves on eight local Perinatal Advisory Committees. Periodic meetings are held with the hi-risk clinic staff to collaborate on referral process. The NICU staff and early intervention staff provide workshops annually at the statewide early intervention conference. State and local early intervention staff also provide trainings to medical community on preservice and inservice levels as requested.

- Brochures are given to clinics and doctors offices.
- Public awareness activities are not specifically geared to the medical community, but they are always included. A few Child Find grant projects have been incorporated that focus on the medical community
- Collaboration with OHSU to provide training to pediatricians
- Local level activities vary.
- First Signs participation
- Not in 2005, but activities have been done in previous years.
- Participation in bi-weekly pediatric rounds at the only medical center.

Appendix R: How States Determine the Extent to Which Information on Early Intervention is Made Available to Parents through Primary Referral Sources

- All new parents receive information about the availability of early intervention services through the Governor's initiative in a new parent's kit.
- Information is provided, however they cannot 'ensure' that families are informed
- We have contracted with the State University's Developmental Care Continuity Program, which is the largest NICU in that state, to provide early intervention services to families and make referrals for follow-up upon discharge. They also work with a parent's advocacy group to inform families about early intervention in the local community and to support families in transitioning form the hospital to home.
- It is the responsibility of the hospital based child find grantees to educate, identify and refer to the NICU for identification and referral process
- NICUs are provided with information packets to distribute to all families. The state has a program in which the infants are referred to a program for follow-up after discharge. This program makes referrals to early intervention.
- New born screening nurses are informed
- They only track referral data by child's birth hospital and provision of referral information and materials to NICU staff

- A member from their agency attends weekly discharge rounds at two hospitals. The state also has a project to implement and IFSP before the infant is discharged
- We fund a project to work with NICU staff in level III nurseries to assist them in making referrals
- We get quarterly reports from the NICU as to the number of referrals to early intervention. We also have a contract to help support the NICU program.
- We make every attempt to have NICU personnel inform parents by providing a ready supply of brochures and other information that can be given to families.
- Local programs meet with the NICU staff to review referral procedures. For the larger NICUs, intake staff is located in the hospital.
- The mandatory birth registry results in follow-up with families to address early intervention. Service coordinators are housed within these units
- The state has a universal birth score project that includes screening for possible reasons to refer to early intervention. The screenings are completed by hospital staff for all births and information is forwarded through the Birth Score office, where they track the number of referrals and provide periodic training for new hospital staff
- We don't ensure but most do refer as a matter of course
- If a physician at the NICU feels that a child needs to be referred they do it with a Part C provider, who then re-evaluates in six months to see if the child is still eligible

- District early intervention staff includes NICUs in the medical outreach within their areas. Packets are also distributed to the families in the NICU. In a program titled “Baby Yourself” expectant mothers receive information as well.
- Information is provided to the NICUs
- Local level efforts entail ongoing collaboration and communication with the NICUs
- We inform and have developmental follow-up clinics at the largest NICU and birthing hospital that includes early intervention staff as well.
- Information is provided to parents through nurses and staff in the nursery and pediatric ward.

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