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An Evaluation of the Early Steps Program Referral Process in Hillsborough County to Detect Delays in Access to Early Intervention Services

by

Jessica Fry Johnson

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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Abstract

Early intervention services are important in obtaining better outcomes for infants with a developmental delay or a condition that may result in a delay. In Florida, a primary resource for providing these services is the Early Steps Program. This study analyzed the Early Steps referral process to identify barriers to prompt access. The guiding hypothesis was if differences exist in key outcomes of the referral process, then these differences may reveal where improvements can be made. Improving access to early intervention should produce better outcomes and reduce the costs of services required later by addressing developmental concerns earlier.

The dataset included records for 10,688 infants referred to the Hillsborough County Early Steps Program between 2006 and 2009. Two measures (age at referral and time to IFSP) represented points within the referral process where delays could be quantified. Age at referral is a measure of how long it takes for a delay to be identified and the infant referred for evaluation. The time from the referral to the date an IFSP is created provides a measure of the delay in beginning services.

Delays in obtaining a referral were associated with being referred by a family member, the referral code Developmental Delay At Risk and barrier codes Child/Family Issues and No Show/Unsuccessful Contact. Delays in completing the IFSP were related to being younger at referral, being referred by one of the sources that made less frequent referrals to Early Steps, an eligibility determination related to behavior concerns, maternal education that stopped at grade 8 or below and being Black.

Chapter 1 Introduction and Background

Introduction

Prompt access to early intervention services is important in obtaining better outcomes for infants diagnosed with a developmental delay or a condition that has a high probability of resulting in developmental delay (McCormick, Brooks-Gunn, Buka, et al., 2006). In Florida, one of the primary resources for providing these services to eligible infants, age 0 – 3, is the Early Steps Program. While many aspects of the Early Steps Program are regularly evaluated by objective third party evaluators such as Florida's Office of Program Policy and Governmental Accountability, the process through which infants are referred to Early Steps has not been evaluated to determine the extent to which it is providing prompt access to all eligible infants. This study analyzed the Early Steps referral process to determine the possible existence of barriers to prompt access for eligible infants. Where such barriers were discovered, the study includes recommendations for resolving or reducing them and improving the referral process.

Background

A Snapshot of Developmental Screening in Hillsborough County, Florida

The process of referring an infant for early intervention services often begins with a routine developmental screening. In 2009, Hess and Marshall conducted an extensive review of developmental screening in Hillsborough County. They surveyed programs and individuals who work with infants and toddlers and asked a range of questions about screening practices. Ten of the 41 respondents indicated they did not provide

developmental screening. The majority of those who did not conduct screenings gave one or more of the following reasons: 1) they were not familiar with appropriate screening instruments, 2) their personnel lacked training in assessing developmental problems, 3) they considered the pay structure for reimbursing agencies for screening to be inadequate and 4) they did not have adequate time and/or staff to conduct screenings. Almost two-thirds of those who did perform screenings reported that screening was required for every child served by their program while the others indicated screenings were conducted when a need was identified by the infant's family or a member of the program's staff or at the request of another program or healthcare practice.

Based on survey responses, approximately 42% of infants who were screened in Hillsborough County, birth to age three, were screened by healthcare practices such as physicians and hospitals. (This is consistent with Early Steps referral data analyzed for this study in which 42.45% of the referrals to Early Steps came from healthcare practices.) A slightly lower percentage (39.7%) was screened by what Hess and Marshall called "intervention providers" with the remaining 18.3% being screened by childcare providers.

Hess and Marshall found extensive variation in the screening instruments used by their respondents; with many programs indicating the use of a combination of formal and informal tools. Hess and Marshal reported that 88% of all respondents and 100% of healthcare practitioners included an informal checklist or an interview process in conducting developmental screenings. The most commonly used formal screening instrument was the Ages and Stages Questionnaire (ASQ). Sixty-nine percent reported using the standard ASQ, while 54% used the ASQ-SE (an instrument for measuring

social and emotional development). Other instruments used by at least 14% of the respondents included the Devereaux (DECA) (42%), Hillsborough County Public Schools' Speech and Language Protocol (30%), Sensory Profile (29%), the Denver II (20%), the Brigance (17%), and Birth-Three (14%). Hess and Marshall indicated their survey revealed the use of more than 20 other validated instruments, although none of them were utilized by more than three respondents.

An interesting note was the absence of a reference to the Battelle Developmental Inventory II; the tool currently used by the Early Steps Program. It was listed on the survey as an option, but its level of use was not reported, indicating that at the time, it had very limited use among those who provided developmental screening in Hillsborough County. One explanation is the Early Steps Program's use of this instrument played a role in its lack of use by other agencies in order to avoid duplication or redundancy.

Hess and Marshall identified multiple themes drawn from the responses to the survey's open-ended questions. These themes are listed briefly below:

1) There is a perceived need for expanded screening, particularly for delays or difficulties in social emotional development.
2) Respondents reported the need for a higher quality of screening efforts, including the effective, consistent use of screening tools and more extensive provider training on the use of screening tools.
3) Reimbursement rates and limited resources are barriers to providing screening for some organizations. Other commonly reported barriers included excessive wait times, lack of follow-through after the initial screening and low levels of parent involvement in assessment, diagnosis and treatment.
4) Respondents recommended more training in assessment, diagnosis and treatment, especially for those who are less experienced in working with infants and children, birth to five, such as school psychologists and counselors.

5) There is a perceived need for improvements in coordination across diverse organizations, for example, a centralized data system that would make data accessible to all who provide developmental screening and those who use the data for diagnostic or prescriptive purposes.

The study also found a number of strengths across the multiple agencies that provide developmental screening for infants and toddlers in Hillsborough County, including "strong community support for screening, collaborative screening models, interagency coordination, and plans to expand screening" (p. 7).

Structure and Purpose of the Early Steps Program

Infants who are referred for early intervention services in Florida may participate, along with their families, in a program called Early Steps. The Early Steps Program offers services to infants and toddlers (birth to thirty-six months) with significant developmental delays or one or more conditions likely to result in a developmental delay. This program began in 1994 and is the vehicle used by the state of Florida to implement Part C of the Individuals with Disabilities Act. Florida's Early Steps Program is operated by the Children's Medical Services Department (CMS) within the Florida Department of Health. CMS contracts with fifteen local Early Steps offices across the state who then coordinate with community agencies and other contracted providers for the delivery of needed support and intervention services. CMS acts as the contract administrator for these local offices and monitors compliance with federal regulations, state policies and contract requirements. CMS also provides technical assistance and training to staff at the local level.

Infants who meet eligibility requirements begin to receive services following the development of an Individualized Family Support Plan based on a comprehensive assessment conducted by Early Steps Program staff. These services include the use of

assistive technology devices (hearing aids or other items used to improve the functional capabilities of the disabled), hearing screenings, counseling, family training, home visits, medical services, occupational therapy, nutrition services, nursing services, vision screenings, speech and language services, physical therapy, access to social workers, coordination of infant and family services as well as transportation and related costs.

The Early Steps Program's initial screening evaluation covers physical concerns such as overall health, hearing and vision. The infant's cognitive capacities are assessed in terms of thinking, learning and problem-solving as well as gross and fine motor skills such as moving, walking, grasping and coordination. Basic communication skills are assessed, as is the infant's ability to play and interact appropriately with others. Finally, the assessment includes an evaluation of the infant's self-help skills such as feeding and dressing herself or himself. The program's early intervention services are intended to enhance infants' development, reduce future costs to the state and local governments by decreasing the need for special education once these infants enter school, and increase the self-sufficiency of families in meeting their children's needs (Office of Program Policy and Governmental Accountability, 2006).

Florida's Early Steps Program was established through the Federal Individuals with Disabilities Education Act (IDEA). Under Part C of this act, known as the Program for Infants and Toddlers with Disabilities, the federal government provides grants to assist states in providing early intervention services. The program is an entitlement for every eligible child and therefore no financial means test is required for eligibility.

Local Early Steps Program service areas range in size from one to fourteen counties. While some of the local area offices self-perform specific services, most

subcontract with other providers. The local area offices are also accountable to provide program and service coordination and administration, collect data for state and federal reporting, and assume fiscal responsibility for service activities and training. For the 2008 fiscal year (ending June 31, 2008) funding for Florida's Early Steps Program totaled $46,764,899. Ninety-four percent of these funds were allocated to direct services for children with special needs, 4% for the CMS headquarters, and 2% for general supervision requirements as prescribed by the Federal regulations. That year, 37,876 children received services through the Early Steps Program. This equates to an average per child expenditure of $1,235.

The Early Steps Program is the funding source of last resort for families seeking early intervention services. The program's policy manual spells out the sequence of where payment for services is sought (Early Steps Program Policy Handbook, 2010).

1) Commercial insurance
2) Medicaid
3) Community funding
4) Other state program funds
5) Other federal program funds
6) IDEA, Part C funds (i.e., Early Steps)

If the family has insurance coverage, service providers will bill the family's plan and any uncovered expenses are paid from the next available source on the list.

The Early Steps Program includes a second component through which infants and toddlers may qualify for early intervention services. The Developmental Evaluation and Intervention program, most often referred to as DEI, is a program

that specifically identifies and follows infants at high risk for developmental delays. The program provides services to infants that have been discharged from Level II or III Neonatal Intensive Care Units (NICU). These infants must meet both medical and financial eligibility and must be determined to need DEI services.

This study will include referral data on infants who qualify for early intervention services through the Part C component of the Early Steps Program and those who are eligible for services based on DEI requirements.

How are Infants Referred to Early Steps?

In the state of Florida, all newborns who are admitted to a Level II or Level III NICU are screened for eligibility for early intervention services delivered through the Early Steps Program. Other infants may be referred to Early Steps for an evaluation by a wide range of sources, including self-referrals by parents or family members. As of July 1, 2010, infants qualify for this program if they have a developmental delay that measures 2.0 standard deviations below the mean, two or more developmental delays that are 1.5 standard deviations below the mean, a birth weight less than 1,200 grams or an established condition that is likely to lead to a developmental delay (Florida Early Steps Program Memo, 2010). Highly prescriptive criteria are used to determine if it would be appropriate to refer an infant or toddler to Early Steps due to vision and/or hearing impairment.

The eligibility criteria were made more restrictive in terms of developmental delays by changing the size of the deficit required to qualify from 1.5 standard deviations to 2.0 standard deviations below the mean if deficits are found in only one domain. If two or more deficits are identified, the size of the delay required to qualify remains 1.5 standard deviations below the mean. However, the criteria were expanded by the

addition of the birth weight criterion; allowing infants who would not have qualified previously to be eligible based on low birth weight, even when no developmental delay has been detected and no other established condition has been documented. The change relative to the assessment of developmental delays was intended to contain costs by limiting access and focusing early intervention services on the neediest infants. On the other hand, the addition of the birth weight criterion is likely to increase the number of infants who qualify for the Early Steps Program. State officials have indicated they believe the result of these changes will be an overall reduction in the number of infants served by the program leading to a net savings (L. M. Price, personal communication, November 17, 2009).

The criteria that became effective on July 1, 2010 differ slightly from what was reported in a national review of Part C eligibility criteria. Shackelford (2006) found that most states consider an infant between birth and 3 years of age to have a developmental delay when a score in any one developmental area obtained through a standardized test is at least 1.5 standard deviations below the age-appropriate mean or observable performance in one or more developmental domains is delayed by 25% or more. In some states, however, only one of the previously mentioned criteria is used for determining eligibility for early intervention services.

According to the Early Steps Handbook (Early Steps Operations Guide: Component 3.0, 2011) the program does not deny services due to alien or citizenship status and there is no state residency or financial eligibility requirement. That is, all children who are in the state and meet Florida's eligibility criteria may be served by Early Steps.

If an established condition is suspected but there is no written confirmation from a physician, then the Local Early Steps Office (LES) is required to identify for the family at least one accessible local diagnostic resource. Eligibility is based on criteria in place on the date eligibility is determined. Children made eligible under previous, broader criteria who do not meet current eligibility criteria are not terminated from services. Verification of eligibility is determined using an appropriate standardized instrument and one or more of the following: observational assessments, developmental inventories, behavioral checklists, adaptive behavior scales or a family report.

Figure 1 provides a diagram of the Early Steps Program referral process. The shaded flowchart shapes reflect activities and decision points that are exclusively components of the referral process. The other shapes represent activities and decisions that are not directly involved in the referral process, but help to place that process in a broader context.

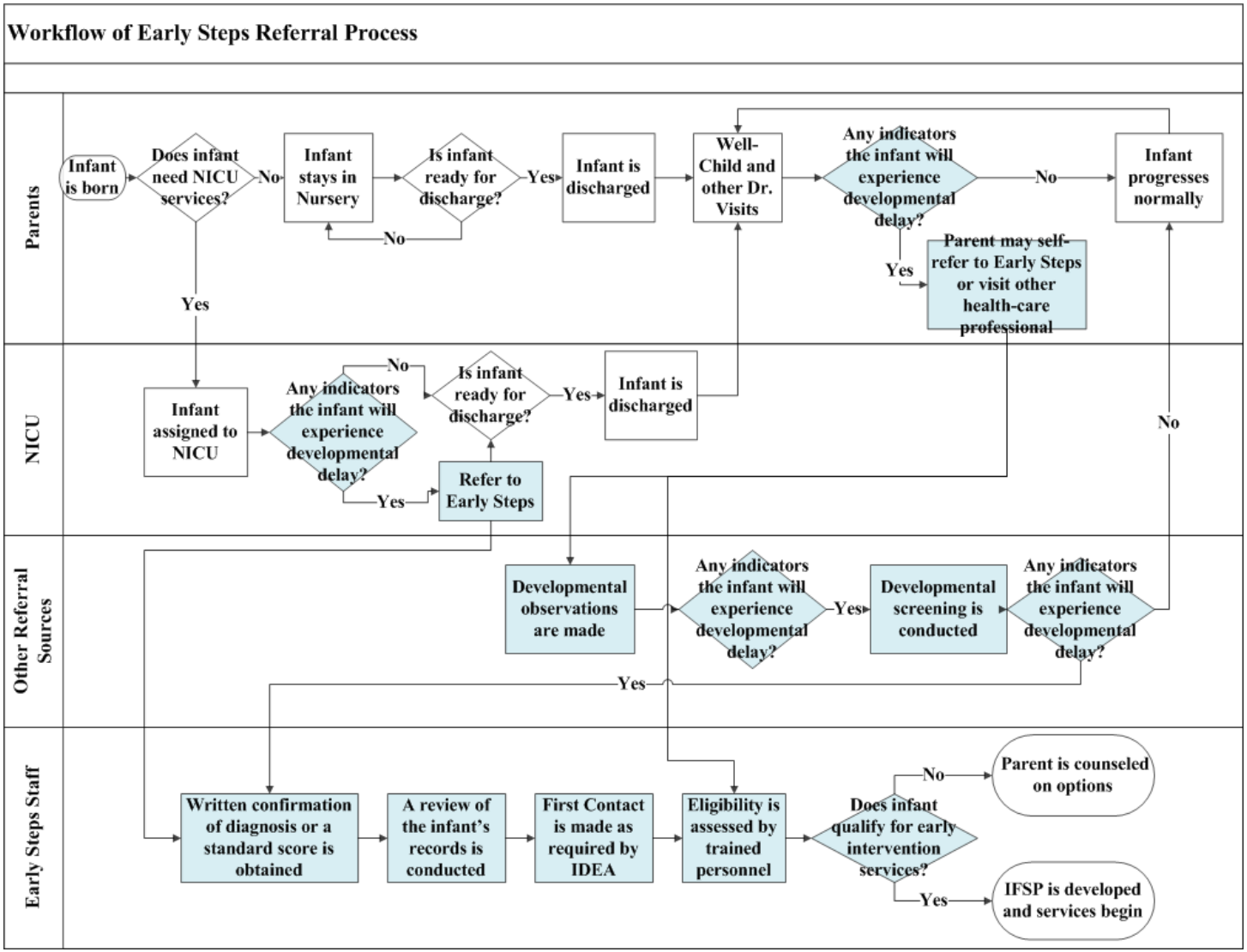

Figure 1. Early Steps Referral Process (A flowchart diagram of the process)

The Early Steps Program documents the referral sources as part of the demographic information collected when an infant is referred for evaluation. For this study, referral and demographic data will be analyzed for all infants referred to the Hillsborough County Early Steps Programs between January 1, 2006 and December 31, 2009. These infants were born from February 15, 2003 through December 18, 2009. Table 1 lists the most common referral sources and the number and percentage of referrals from each source included in the sample analyzed for this study:

Table 1. *Referral Sources, Number and Percentage of Referrals*

Referral Source	ES Referral Source Code	Number of Referrals Made	Percentage of Total Referrals in Sample
Physician	4	2,322	21.73%
NICU	6	2,215	20.72%
Self/Family	7	2,150	20.12%
Community Agency/Provider	A	1,671	15.63%
School/FDLRS	5	659	6.17%
Other	9	452	4.23%
Hospital (Not NICU/PICU)	N	362	3.39%
Public Health Agency	8	239	2.24%
Children's Medical Services	M	172	1.61%
Transfer from another Florida ES Center	E	140	1.31%
Protective Investigators	1	116	1.09%
Child Protection Team	C	74	0.69%
Transfer from non-Florida Early Intervention Program	X	58	0.54%
Subsidized Childcare/ECE Center	S	43	0.40%

The Need for Prompt Access to Early Intervention Services

The importance of referral to early intervention services as soon as a developmental delay or other relevant condition is identified is a widely held assumption. However, the research support for the idea that "earlier is better" is sparse. Most studies on the effectiveness of early intervention services focus on outcomes regardless of when the infant or child was referred for these services. Studies that deal directly with the issue of the benefits of prompt access tend to be older or focus on the negative impact of delaying access to needed interventions. For example, a study by Sharkey et al. (1990) examined the age of referral and the effect of early intervention for children with physical handicaps. Children who were referred for early intervention services before 9 months of age were compared with children referred after 9 months of age on a range of developmental tests. At 18 months of age, the children in the group referred at an earlier age showed greater developmental progress in acquiring the skills measured in all six areas tested: perceptual-fine motor ($p < 0.0003$), cognition ($p < 0.0001$), language ($p < 0.0004$), social-emotional ($p < 0.0001$), self-care ($p < 0.0001$), and gross motor ($p < 0.0002$). The authors concluded that, "at least in the short term, there is a critical age for onset of intervention to achieve the most benefit for the developmentally disabled child" (p. 163).

Without formal intervention, Shonkoff and Phillips (2000) found a trend of declining performance across the first 5 years of life on developmental measures for children with a variety of cognitive disabilities, such as Down syndrome. Similarly, a report from the Zero to Three Policy Center (Oser & Cohen, 2003) cites a study by the Mathematica Policy Research, Inc. and Columbia University's Center for Children and Families at Teacher's College that found that infants and toddlers who

scored in the “at-risk” range of developmental functioning (i.e., below the mean of national norms) and did not receive services frequently moved into the lowest functioning at-risk group as they grew older.

In another older study, Yoshinaga-Itano, Sedy, Coulter, et al. (1998) compared the receptive and expressive language abilities of 72 deaf or hard-of-hearing children whose hearing losses were identified by 6 months of age with 78 children whose hearing losses were identified after the age of 6 months. All of the children received early intervention services within an average of 2 months after identification. The participants' receptive and expressive language abilities were measured using the Minnesota Child Development Inventory. Children whose hearing losses were identified by six months of age demonstrated significantly better language scores than children identified after 6 months of age. For children with normal cognitive abilities, this language advantage was found across all test ages, communication modes, degrees of hearing loss, and socioeconomic strata. It also was independent of gender, minority status, and the presence or absence of additional disabilities. The authors reported that significantly better language development was associated with early identification of hearing loss and early intervention. There was no significant difference between the earlier- and later-identified groups on several variables frequently associated with language ability in deaf and hard-of-hearing children. They concluded that the variable on which the two groups differed (age of identification and subsequent start of intervention) must be considered as a potential explanation for the language advantage documented for the group identified at an earlier age.

In 2007, the American Academy of Pediatrics published a position statement on the need for early identification and treatment of hearing impairment in which they endorsed early detection of and intervention for infants with hearing loss. They stated that the goal of early hearing impairment detection and intervention was to maximize linguistic competence and literacy development for children who are deaf or hard of hearing. Their statement stressed that because hearing loss deprives infants and young children appropriate opportunities to learn language; they fall behind their hearing peers in communication, cognition, reading, and social-emotional development. They cited studies indicating that such delays can ultimately result in lower educational and employment levels by the time these children reach adulthood. The statement recommends that all infants should be given a hearing screening no later than 1 month of age and that those who do not pass the screening should have a comprehensive audiological evaluation by the time they reach three months of age. Infants with confirmed hearing loss were recommended for early intervention no later than six months of age.

What Aspects of the Early Steps Program have been Evaluated?

The Office of Program Policy and Governmental Accountability (OPPAGA) supports the Florida Legislature by providing evaluative research and objective analyses to promote government accountability and the efficient and effective use of public resources (OPPAGA Report 08-44, 2008). Since 2006, OPPAGA has performed multiple reviews of the Early Steps Program. Their reports have focused on a range of program components and related issues. These include the shift from a clinic-based service model to a "natural environment" model, changes in enrollment, alignment of budget authority with federal grant amounts, provider participation

rates and the structure of contracts that outline program oversight. The referral process has not been addressed by OPPAGA during any of its recent reviews.

In 2006, OPPAGA examined the Early Steps Program's enrollment, the implementation of a new model for delivery of services, funding levels and policies as well as a change in how service providers were assigned to work with eligible infants. Part of their assessment focused on the number of children with an active case plan on a specific date (December 1 of each year of the evaluation period). The OPPAGA audit of the Early Steps Program's records found that this number decreased each year from a high of 16,894 on December 1, 2002 to 12,214 on December 1, 2005 (a decline of almost 28%). Using an analysis similar to one employed by the federal government, OPPAGA compared this number to US Census data for Florida to determine the percentage of Florida's population of children zero to three years of age served by Early Steps. This percentage declined in 2003-04 and 2004-05 after a slight increase in 2002-03. Early Steps Program administrators suggested that the decline in participation for 2004-05 may have been due to the series of hurricanes that hit the state during late summer and early fall of that year. The impact of these storms on Florida's communities and families may have made it difficult to identify and serve eligible children. According to the OPPAGA report, an additional factor contributing to the lower numbers may have been under-reporting of infants and families served because of delays in data entry at the local level (OPPAGA Report 06-14, 2006).

During the same period of time, the Early Steps Program responded to federal direction by making a significant change in its service delivery model, moving from

a clinic-based services model, in which parents brought their children to participating clinics to receive early intervention services to providing these services in a "natural environment." This change involved providing services in the infant's home or in a community program that included children without disabilities.

The natural environment model had been a federal priority for some time before implementation was initiated in Florida in July 2004. The original requirement that early intervention take place in settings in which children without disabilities participate was in IDEA Part C in 1989 (Michigan Department of Education, 2008). In the 1991 amendments to IDEA Part C, Congress added the language of "natural environments" to their definition of early intervention services. The federal statute also required that the Individualized Family Service Plan (IFSP) include a description of how services will be provided in the child's natural environment and, if not, a justification for why they cannot be provided in the natural environment. OPPAGA's report mentioned the Florida Early Steps Program's "historical reliance on providers that used a clinic-based model and the difficulty of convincing these providers to provide services in natural environments" as important factors in Florida's delay in moving to this model (OPPAGA Report 06-14, 2006, p. 3).

The same OPPAGA report found that for some Early Steps area offices, up to 84% of the local early intervention services providers expressed a reluctance to participate under the new service model. These service providers gave several reasons for their lack of interest, including financial disincentives associated with reimbursement rates that were equal to or lower than Medicaid, the shift to the

natural environment model, risk-sharing agreements in which providers would accept lower reimbursement rates during years when program funding shortfalls occurred and the implementation of a primary service provider model. These providers reported to OPPAGA investigators that the program's reimbursement rates discouraged broader participation by local service providers because they did not currently reflect the increased costs associated with implementing the natural environment model. They mentioned that due to travel time, the number of infants and families they were capable of serving would decrease under the new program model because the providers must send therapist or other relevant healthcare professionals to each child's home or a facility in the infant's neighborhood instead of the family bringing the infant to a centrally-located clinic where the services could be provided more efficiently. The increased expense made it less profitable for almost all service providers.

OPPAGA also found that some providers indicated that local program offices had required them to accept a risk-sharing fee structure in response to funding deficits. The OPPAGA report cited a decision by one area Early Steps Program office as an example in which providers accepted a 10% reduction in their reimbursement rates to cover program deficits. Several other Early Steps Program offices reported having procedures in place to adjust rates based on the availability of funds and still others indicated they planned to develop either risk-sharing or rate adjustment algorithms to control costs.

The 2006 OPPAGA evaluation also included the impact of a change in state policy requiring that a primary provider be designated for each infant rather than

allowing the infant to be served by various therapists or other providers. Under this model, an individual is selected to be the primary provider who is then expected to confer with the other members of a support team to determine how to deliver services during routine visits with the infant and family. The primary provider makes the majority of visits to the home while other team members may visit less frequently, depending on the infant's needs and progress. The OPPAGA report indicated some providers were concerned that this model would create less than ideal alignment between an infant's needs and the experience and expertise of the primary service provider.

Following the 2006 OPPAGA evaluation, the Early Steps Program implemented a new rate structure that addressed service providers' concerns with the practice of assigning a primary care provider and support team as well as other issues with providing services in a natural environment. The revised reimbursement rate structure paid providers for consultations with team members that were part of developing, delivering and assessing each infant's service plan. The revised rate structure also did much to equalize the wide variation across Early Steps Program area offices in travel reimbursement rates that were in effect at the time of the 2006 review.

Another issue from the 2006 review that was addressed in 2007 was the timeliness and completeness of data entry by area program offices. The Early Steps Program implemented a timeliness standard as a part of area office contracts. OPPAGA's 2008 evaluation found that all but one of the area offices met the standard of submitting at least 90% of service-related data within 60 days after the

end of the month in which the services were delivered. OPPAGA also recommended that the Early Steps Program further modify their contracts with area offices to require that monitoring plans are submitted at the beginning of each fiscal year as a means to improve oversight of the local offices. Area offices may choose the method and frequency of their monitoring efforts.

Problem Statement

No formal evaluation of the Early Steps referral process has been conducted to examine how well the current referral process provides prompt access to early intervention services for eligible infants. Without such an analysis, stakeholders may not know with certainty the extent to which eligible infants are able to begin receiving these needed services in a timely manner.

Purpose of the Study

The purpose of this study was to determine the existence of barriers to prompt access to early intervention services in the Early Steps referral process so that efforts to make the process more efficient and effective could be targeted more precisely. This purpose adds value by increasing the likelihood that suggested improvement result in improving prompt access to early intervention services to achieve better outcomes for infants and their families as well as reducing costs for intervention services required after the age of 3.

Chapter 2 Literature Review

Assessing Referral Processes

Referral processes are most typically evaluated based on the appropriateness of the referrals they produce. While this type of evaluation focuses on the validity of the referrals, it does not address other aspects of the referral process such as timeliness or efficiency. Shevell, Majnemer, Rosenbaum, & Abrahamowicz (2001) provide an example of the evaluation of a referral process that assesses the validity of the referrals by comparing the referral reason with what was ultimately determined to be the diagnosis for children suspected of having a developmental delay. The objective of their study was to determine the profile and pattern of referral to subspecialty clinics for young children with suspected developmental delay together with the factors prompting their referral. 224 children less than 5 years of age referred to either developmental pediatrics or pediatric neurology clinics at a single tertiary hospital over an 18-month period were included in the study sample. They utilized demographic and referral data collected at intake and the final developmental delay diagnosis to make the comparison. For slightly more than one third of the children (75/224), the delay diagnosed following evaluation by a specialist was different from that initially suspected by the referring physician.

Other studies have compared rates of identification, as measured by participation in early intervention services, to the known prevalence of relevant conditions to determine if the referral process was identifying an appropriate

percentage of the infant population. In one such study, Sices (2007) found that while the estimated prevalence of developmental delays in young children is at least 10 percent, only 2.3 percent of children between birth and age 3 participated in IDEA Part C Early Intervention (EI) programs in 2005. This means that from a national perspective the process of developmental surveillance and screening leaves nearly four out of five potentially eligible children without access to early intervention services. By comparison, in Hillsborough County the percentage of infants who receive early intervention services is almost double the national average. There were 69,651 infants born in Hillsborough County from 2006 through 2009. Of these, 7,120 were referred for evaluation by Early Steps and over half (3,980) qualified and had an IFSP developed. This means that 3.97% of the total live births in Hillsborough County during this period (2006 – 2009) qualified for early intervention services through the Early Steps Program.

There are, however, a number of studies that look specifically at delays that occur at different points in the referral process. Shevell et al. (2001) cited above as an example of studies that examine the validity of referrals also looked at the timeliness of the outcomes of the referral process. They found that for children diagnosed with global developmental delays, mean age at the time their parent(s) expressed a concern related to their development was 19 months and that an assessment related to that concern did not take place until 16 months later (on average), when the mean age of the infants was 35 months. For children with speech and language delays, parents had concerns at a mean age of 27 months and again the average wait for an assessment was 16 months, when the child was now 43 months

old. Overall, most parents had concerns about their child's development during the second year of life, but diagnostic assessments by specialists were often not conducted until age 3 1/2 or 4.

A large scale study (3338 families of infants at risk for developmental delays) by Bailey, Hebbeler, Scarborough, Spiker & Mallik (2004) found very different timeframes for the same elements of the referral process. They reported that on average, families expressed a concern about their child at 7.4 months, received a diagnosis 1.4 months later, were referred to early intervention services 5.2 months after the diagnosis and had an individualized service plan developed 1.7 months later, when the infant was 15.7 months of age. The differences between the findings of these two studies might be explained by differences in the methodology used to obtain the data.

Table 2 summarizes these studies and identifies a benchmark that can be utilized in the assessment of the outcomes of the Early Steps referral process within this study.

Table 2. *Methods and Findings Related to the Assessment of Referral Processes, Benchmarks and Comparisons*

Study Author(s) (Year Published)	Method of Assessment	Relevant Findings	Study Benchmark	Hillsborough Early Steps Data
Sices (2007)	Compare rates of identification, as measured by participation in early intervention services, to the known prevalence of these conditions.	While the prevalence of delays in young children is at least 10 percent, only 2.3 percent of children between birth and age 3 participated in IDEA Part C Early Intervention (EI) programs in 2005. This means that nearly four of five potentially eligible children did not participate.	2.3% of children between birth and age 3 received early intervention services through Part C	3.97% (2,768) of the infants born in Hillsborough County during the study period received early intervention services through Early Steps (Part C)
Shevell, M. Majnemer, A. Rosenbaum, P. & Abrahamowicz, M. (2001)	Calculate delay between initial concern and assessment	For children diagnosed with global developmental delays, mean age at initial parental concern was 19 months, with assessment on average 16 months later, at 35 months. For children with speech and language delays, parents had concerns at a mean age of 27 months, with assessment on average 16 months later, at 43 months. Overall, most parents had concerns about their child's development during the second year of life, but diagnostic assessments by specialists were often not conducted until age 3 1/2 or 4.	Mean age at assessment: Global (See note) developmental delay = 35 months Speech = 43 months Gross/Fine Motor = 22 months	Mean age at assessment: Global developmental delay = 20 months Speech = 26 months Gross/Fine Motor = 14 months

Study Author(s) (Year Published)	Method of Assessment	Relevant Findings	Study Benchmark	Hillsborough Early Steps Data
Bailey, D., Hebbeler, K. Scarborough, A., Spiker, D. & Mallik, S. (2004).	Calculate delay between initial concern and referral	On average, families reported a concern about their child at 7.4 months, received a diagnosis 1.4 months later, were referred to Early Intervention programs 5.2 months after the diagnosis, and had a service plan developed 1.7 months later, at 15.7 months of age	Average age at referral = 14 months Average age at IFSP = 15.7 months	Average age at referral = 16.4 months Average age at IFSP = 20 months
Shevell, M. Majnemer, A. Rosenbaum, P. & Abrahamowicz, M. (2001)	Alignment of referral reason and subsequent evaluation results	For 75 children in total (35.3% of the study sample), the disability subtype ultimately diagnosed subsequent to specialty and ancillary evaluation was different from that originally suspected.	35.3% of referral reasons did not match specialty diagnosis	67% of referral reasons did not match diagnosis as determined by ES assessment

Note. Global developmental delay was defined in Shevell et al. as a significant delay in two or more developmental domains; in the Hillsborough County data, it is represented by the average age at initial IFSP for all infants in the study sample for whom an IFSP date was documented (n = 5,468)

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Known issues associated with the referral process for early intervention services

This section will highlight findings in the literature review that identify issues arising from the referral processes used to refer infants for early intervention services. These issues will add to and clarify the analysis of Early Steps referral patterns completed for this study.

Unnecessary Complexities. Deckard, Borkowski, Diaz, Sanchez and Boisette (2010) write that "unnecessary complexities in the referral process exacerbate delays in the receipt of services and impact patient quality of care" (p. 125). A report by the Institute of Medicine (IOM, 2001) describes how an overly complex delivery process that involves too many steps and excessive "patient handoffs" will result in slower responsiveness, an increase in negative outcomes and wasted time, energy and money. This report identified timeliness (defined as reducing the amount of time patients wait to receive services and the time healthcare professionals spend waiting for action to be taken or information to be provided) and efficiency (defined as avoiding waste, including waste of equipment, time, supplies, ideas and energy) as important goals for improving healthcare systems.

If there are areas of "unnecessary complexities" or other barriers to prompt access to early intervention services for eligible infants, then those who are engaged in the day to day use of the process should be able to identify them. This evaluation will engage important stakeholders in looking objectively at the referral process and identifying areas where changes might produce a more timely and efficient process.

Gender Disparity. A large difference appears across multiple studies in the referral rates for boys and girls with boys almost always being referred for early intervention services much more frequently. Table 3 provides a sample of studies

that reflect the range of disparities in the gender composition of various populations of infants referred for these services. A preliminary analysis of Early Steps Program referrals conducted for this study showed a similar pattern in the gender breakdown of infants referred for Early Steps evaluation with 62% males. (See the last row of Table 3.)

National data on births by gender, labeled "sex ratio" by the Centers for Disease Control, have shown an imbalance toward a higher proportion of boys since 1940. The ratio for 2007 (the latest available and within the timeframe of births for this study) was 1,047 males for every 1,000 females or 51.14% males.

Table 3. *Gender Proportions of Infants Referred for Early Intervention Services*

Study Authors (Year Published)	Total Infants	Males Percent (Number)	Females Percent (Number)
Kalia, Visintainer, Brumberg, Pici, & Kase (2009)	127	54% (69)	46% (58)
Barfield, et al. (2008)	1,233(See note)	50% 615	50% 618
Clements, Barfield, Kotelchuck, Lee, & Wilber (2005)	219,037	51.2 (112,105)	48.8 (106,932)
Bailey, Hebbeler, Scarborough, Spiker, & Mallik (2004).	3224	60% (1934)	40% (1290)
Shevell, Majnemer, Rosenbaum, & Abrahamowicz (2001)	224	74% (166)	26% (58)
Early Steps data from Hillsborough County (referral dates Jan. 1, 2006 – Dec. 31, 2009	10,688	62% (6617)	38% (4071)

Note. Study involved only infants weighing less than 1,200 grams at birth

Physician Referrals. In the data analysis conducted during the planning of this study, it was noted that physicians referred more infants for early intervention services than any other referral sources. Therefore, understanding the referral

patterns of physicians is a top priority. From the literature review, the issues associated with physicians' referrals arise primarily from practices related to developmental surveillance and developmental screening.

Developmental Surveillance. The role of primary care providers, both physicians and nurses, in identifying infants with developmental delays at a young age differs significantly from that of others who make referrals to the Early Steps Program. Because they are in more regular contact with the infant and family, they see the infant's development over time. This allows them to make multiple comparisons over time against age-appropriate benchmarks and places them in a position to make the earliest identification of potential or actual developmental delays. Their more intimate knowledge of the infant and family gives them a clearer context for making judgments about developmental markers that are outside the range of normal development. When primary care providers monitor an infant's developmental progress on an on-going basis, it is referred to as developmental surveillance.

Developmental surveillance is defined by Rydz, Shevell, Majnemer, & Oskoui (2005, p.3) as "an ongoing process of monitoring the status of a child by gathering information about the child's development and behavior from multiple sources, including skillful direct observation of the child's behavior and elicitation of concerns from parents and relevant professionals." This process may also include making a record of relevant developmental history and the use of an age-appropriate checklist to document when developmental milestones are achieved.

The American Academy of Pediatrics (AAP) has repeatedly stated their support for developmental surveillance as an important means to identify infants with one or more developmental delays (King et al., 2010). Because it engages the parent or other family members in collecting data about the infant's growth and development, it can produce the added benefit of encouraging more frequent parent/child interactions that stimulate and enhance the infant's development (Rydz, et al., 2005). Talking with parents about their infant's progress also gives the primary health care provider a better picture of what the parent understands about his or her infant's development and provides an opening for sharing relevant and useful information and advice. These conversations can make it easier for the parent to spot problems earlier and feel more at ease in bringing potential problems to the physician's or nurse's attention.

Even though most primary care providers perform some type of developmental surveillance, recent studies have found that clinical impressions are not sufficiently effective in assessing possible developmental delays. For example, Marks, Hix-Small, Clark & Newman (2009) found that when pediatricians relied on developmental impression to identify infants who should be referred for early intervention services, they made referrals for 9.5% of the pre-term infants whose parents brought them for well-child visits or other reasons while full-term infants were referred at a rate of 5.6%. When they used a validated screening instrument, the percentage of preterm infants who were referred for early intervention services rose to 26.2% and the rate for term infants climbed to 8.1%.

While the benefits of developmental surveillance are well-understood, making it a routine part of contact with infants and families faces some significant obstacles. The obstacle identified most frequently involves time. Time constraints around an office visit may not allow the health care provider to spend the time necessary to conduct surveillance observations and interviews; especially if the physician or nurse is responding to health concerns perceived as more urgent by the parent. Johnson (2000 cited in Rydz, et al., 2005) reported that many pediatric practices had shortened office visits to an average of 12 minutes, limiting the health care provider's ability to conduct a comprehensive developmental surveillance. A later study by Merline, Olson and Cull (2009) found that the length of pediatric visits for patients of all ages had actually increased 14% from 1994 (14.2 min) to 2006 (16.4 min), but visits for children 0 to 5 were the shortest, averaging 14.6 minutes. They cite the increased expectations for what providers will do during an office visit as a possible source of the widely-held impression that pediatric visits are too short for conducting developmental surveillance on a regular basis.

To be truly effective, developmental surveillance must be conducted over time so physicians and nurses are able to construct a long-term picture of the infant's development. In a highly mobile society, it is not uncommon for an infant to be seen by several different health care providers in different practices over the course of the first three years of life. Even if records are shared across these practices, the firsthand knowledge that is so important in tracking potential developmental delays is lost. In addition, the effectiveness of developmental surveillance is dependent on the health care provider's own expertise and experience. Without adequate training and study of

developmental and family issues the physician or nurse may not be fully aware of early markers of developmental delay or they may not understand how to communicate with culturally diverse families and therefore, miss out on important information that only family members can provide (Rydz, et al., 2005).

Developmental Screening. Developmental screening is a different strategy from developmental surveillance, but both result in early identification of infants and children with current or potential developmental delays. Rydz et al. (2005) describe developmental screening as "the process of proactively testing whole populations of children to identify those at high risk of clinically significant but, as yet, unsuspected deviations or delay from normality." Although these screenings do not produce a definitive diagnosis of specific developmental delays, developmental screening can identify infants who require more in-depth assessment. The use of standardized tools as a routine part of each well-child or other office visits can serve to remind health care providers to allocate time to developmental screening. As stated earlier, developmental screening increases the percentage of both pre-term and term infants who are referred for evaluation for early intervention services when compared with referrals based only on clinical impressions (Marks, Hix-Small, Clark & Newman 2009).

Examples of Developmental Screening Instruments.

Most developmental screening instruments have items that are that address each of these five domains (Black, 2004).

Personal-Social: Measures behaviors children demonstrate during typical social interactions. These include commonplace interactions with adults, the

expression of feelings or affect, behaviors that indicate the child's self-image, how the child interacts with other children and behaviors used to cope with a range of circumstances.

Adaptive: Self-help skills such as those behaviors that enable the child to become increasingly more independent in daily living tasks such as feeding, dressing and personal toileting needs. This domain also includes task-related skills that reflect the child's ability to attend to specific stimuli for increasingly longer periods of time, to assume personal responsibility for his or her actions, and to start some purposeful activity and follow through appropriately until completion.

Motor: Measured behaviors include muscle control, coordination, crawling or walking, fine muscle and perceptual motor skills. This domain includes differentiated measures of gross motor development, i.e., use of large muscles, observations of movement and control and fine motor development such as hand and finger skills; and hand-eye coordination.

Communication: Measures the child's ability to understand and use language to communicate for a range of daily living purposes. Behaviors measured include the child's receptive and expressive communication of information, thoughts and ideas through verbal and nonverbal means.

Cognitive: Measures skills and abilities that are cognitive rather than physical in nature. Abilities measured include perceptual discrimination, memory and reasoning. Tasks for older children may include comparison among objects based on physical features, sequencing events, grouping and sorting similar objects and identifying similarities and differences among objects based on shared attributes.

As Hess and Marshall (2009) found in their review of screening practices in Hillsborough County, there are many widely-used developmental screening tools. Several of the most commonly used instruments are described here.

Parents' Evaluation of Developmental Status: PEDS consists of two open-ended questions and eight yes/no questions. It can be administered in approximately five minutes through an interview approach but parents can complete it independently. It is chosen by many busy practices because it can be completed by a parent while waiting to see the doctor or even at home before a well-child visit.

PEDS was first utilized in 1997. It has been found to correctly identify 74% to 79% of those infants and children who actually have a developmental delay and can identify those who do not have a developmental delay 70% to 80% of the time. It can be used with ages zero to eight years to detect developmental delays and behavioral problems and is appropriate across all levels of parental education, socioeconomic status and parenting experience (Hamilton, 2006).

The PEDS produces a risk rating of low, medium or high. Children at high risk should be referred for more comprehensive assessment; early validity studies reported by Glascoe (1997) found approximately 70% of infants who scored in the high risk range were found to have disabilities or substantial delays upon further evaluation. Children at medium risk should also be recommended for further screening, as approximately 30% were found to have disabilities or substantial delays.

Age and Stages Questionnaires: The ASQ series (which was originally known as the Infant Monitoring Questionnaires) was developed by Bricker, Squires, and colleagues at the University of Oregon (Bricker & Squires, 1999). Like the PEDS, it is a user-

friendly screening tool that utilizes parents' reporting of concerns and issues. The questions are written at a fourth- to sixth-grade reading level, making it accessible to most parents. Parents can typically complete the 30 items in 10 to 20 minutes and it can be scored in less than 5 minutes (Hamilton, 2006).

The ASQ is a series of 19 age-specific questionnaires that screen communication, gross motor, fine motor, problem-solving, and personal adaptive skills. It uses a pass/fail score for each domain. The ASQ is appropriate for infants as young as four months and children as old as five years. It was normed on 2,008 children from diverse ethnic and socioeconomic backgrounds, including children from Spanish speaking families. Its sensitivity is in the moderate to high range (0.70–0.90). Specificity is also moderate to high (0.76–0.91). It provides a cutoff score in each of five domains of development. Infants scoring below that cutoff score should be recommended for further evaluation.

Battelle Developmental Inventory Screening Tool, 2nd edition: The BDI-ST is a directly administered tool. It is designed to screen personal-social, adaptive, motor, communication, and cognitive development. Like the ASQ, it results in pass/fail scores but it adds an age equivalent. It can be modified for children with special needs and is appropriate for ages birth to 95 months. Administration requires from 10 to 15 minutes for infants up to 3 years old and can require 20 to 30 minutes for children older than 3 years.

The 2nd edition was normed on 2,500 children. The norm group was structured so that its demographic information was in line with the 2000 US Census data. Additional bias reviews were performed to adjust for gender and ethnicity concerns. It has a sensitivity rating in the moderate to high range (0.72–0.93) and specificity of 0.79– 0.88,

which places it in the moderate range. It uses a quantitative scaled score in all five domains. These are compared with established cutoffs to determine the need for referral.

Bayley Infant Neurodevelopmental Screen : The BINS is another directly administered tool comprised of a series of six item sets that screen basic neurological functions, receptive functions such as visual, auditory and tactile input, expressive functions such as oral, fine and gross motor skills and cognitive processes. It assigns a risk category (low, moderate, high risk) based on the results of set of items. The Bayley requires about ten minutes to administer and can be used with infants as young as three months and as old as 24 months. Norming was done on a group of approximately 1,700 children, as with the ASQ, the norming group was selected to match the 2000 US Census. Measures of sensitivity place it in the moderate range (0.75–0.86) and specificity ratings are also in the moderate range (0.75–0.86).

Brigance Screens-II: The Brigance is also a directly administered tool composed of a series of nine forms screening articulation, expressive and receptive language, gross motor, fine motor, general knowledge and personal social skills as well as pre-academic skills when these are relevant. It is valid for use with infants from birth to 23 months of age using the parents' reported observations. The overall acceptable range of use is birth to 90 months. It takes from 10 to 15 minutes to administer. The Brigance II was normed on 1,156 children from 29 clinical sites in 21 states. It has a reported sensitivity in the moderate range (0.70–0.80) with an identical range of specificity: Results are reported on a criterion-based scale and no normative data are presented.

Child Development Inventory: The CDI is a parent-completed questionnaire that measures the child's social skills, development of self-help skills, gross and fine motor

development as well as language and general development skills. The scoring results in developmental quotients and age equivalents for different developmental domains. It can be used with children 18 months up to six years of age. It is much longer than the other instruments described here; with 300 items and a range of 30 to 50 minutes to complete. There are some concerns about the norming group since it included a significant number of children from a homogeneous area south of St. Paul, MN. It has reported sensitivity in the moderate to high range (0.80–1.0) and slightly higher overall specificity (0.94–0.96).

The Status of Developmental Screening.

Reports to Congress on the implementation of IDEA Part C show consistent levels of participation just above 2% of infants in the United States (IDEAdata.org. 2007). Sices (2007) cites multiple studies that confirm about 10% of infants and children are identified with some form of developmental delay by the time they are school age. The gap between these estimates creates a sense of urgency for health care providers to employ appropriate screening instruments to supplement developmental surveillance. To address this gap, the American Academy of Pediatrics (AAP) issued an updated policy statement on developmental surveillance and screening for children from birth to 3 (AAP, 2006). Their recommendations included three points: 1) conduct developmental surveillance at all well child visits, 2) conduct structured developmental screenings using a standardized instrument at 9, 18, and 24 or 30 months of age and 3) refer infants judged to be at risk for developmental delays for more in-depth developmental and medical evaluations so that eligible infants could begin receiving early-intervention services promptly.

King et al. (2010) conducted a large-scale study to assess the extent to which pediatric practices were able to implement the AAP recommendations for developmental

screening and referrals. Nearly all of the practices who participated in the study selected parent-completed screening instruments, primarily as a time-saving approach to collecting observational data. Participating practices reported screening more than 85% of infants they saw at the AAP's recommended ages (9, 18, and 24 or 30 months). They indicated this was doable if they divided up the responsibilities among the practice's staff. Despite these efforts at making the process as efficient as possible, many practices struggled when things were busier than usual and when they experienced a turnover in staff. A majority of practices reported difficulty or unwillingness to adhere to three of the AAP's recommendations: 1) to conduct a 30-month visit in addition to the more typical 9, 12 and 24 month visits; 2) to administer a standardized screening when their surveillance suggested a potential concern; and 3) to submit simultaneous referrals to medical specialists and local early intervention services programs. Overall, King et al. reported practices had referred only 61% of infants who failed screenings. Many practices also struggled to track their referrals to determine if parents followed through with obtaining an evaluation.

The Benefits of Access to Early Intervention Services

The following sections of this literature review dwell in much detail on the implications of pre-term birth. This lengthy review is necessary for two reasons. First, a significant proportion of the infants in the dataset were born with a gestational age of less than 37 weeks (3,047 out of 10,688 or 28.5%; including 82% of the NICU babies). Second, this detailed review underscores the importance of prompt access to early intervention services for these infants. Seeing clearly the challenges they face and the deficits with which they begin life, the urgency of ensuring high quality interventions at the earliest time possible becomes more

evident. There is a window of opportunity for pre-term infants; and while they may not catch up with their full-term age mates, providing prompt access to the services they need can make a significant difference in the options that will be open to them as they progress through school and into adulthood.

For the period of 1985 to 1988, 9.7% of live births to resident mothers in the United States involved gestation less than 37 weeks (Adams, et al., 2009). By 2004, 12.5% of all live births in the United States were born preterm (Kalia, Visintainer, Brumberg, Pici, & Kase, 2009). According to the National Vital Statistics Report, (2005) the rate of very preterm births was stable from 1990 through 2003, but larger numbers of moderately-preterm infants accounted for the increased rate of preterm births. In fact, moderately-preterm infants now make up over 70% of all preterm births in the United States each year (Davidoff, et al., 2006).

Health Outcomes for Very Preterm Infants. Survival rates for very preterm infants have trended upward since the mid-1980's. The increased survival rate for this population has been "attributed to the combined effects of an increase in assisted ventilation at delivery, surfactant therapy and possibly increased use of antenatal steroid therapy" (Hack and Fanaroff, 2000, p. 101). As this trend was investigated more thoroughly, concerns arose over the outcomes faced by infants whose survival would have been doubtful just a few years earlier (Hack & Fanaroff, 2000; Hoekstra, Ferrara, Couser, Payne & Connett, 2004; Hintz, Kendrick, Vohr, Poole & Higgins, 2005).

These concerns and their potential consequences were expressed clearly in a review of outcomes for infants of less than 25 weeks GA by (Hintz, Kendrick, Vohr, Poole & Higgins, 2005, p. 1645-6).

> If resuscitation and technical interventions are successful in saving the lives of the most premature infants but have no measurable effect on long-term outcomes, increasing numbers of disabled, formerly premature infants will result, affecting the resources of family, schools, and society. Furthermore, if major in-hospital morbidities, some of which have been linked with adverse neurosensory and cognitive findings are more common among these high-risk infants, then outcomes may in fact be getting worse

It is at first counterintuitive that medical interventions that increase survival for very preterm infants would contribute to increased incidence rates of serious health problems, but when considered in light of the established finding that these health concerns are inversely related to gestational age and birth weight, this unintended outcome appears logical. Hack and Fanaroff (2000) confirmed that this relationship between morbidities of prematurity and gestational age extends to very preterm infants through an extensive review of relevant studies published during the 1990's. Their review showed that survival rates increased with GA for very preterm infants. The studies they reviewed also showed a consistent trend for decreasing morbidities as GA increased. (See Table 4.)

Table 4. *Outcomes of Very Preterm Infants by Gestational Age*

Finding	Range of Percentages Reported by GA		
	23 Weeks	24 Weeks	25 Weeks
Survival	2 to 35	17 to 62	35 to 72
Chronic lung disease	57 to 86	33 to 89	16 to 71
Severe cerebral ultrasound abnormality	10 to 83	9 to 64	7 to 22
Severe disability (Note 1)	34 (Note 2)	22 to 45	12 to 35

Compiled from Hack, M. and Fanaroff, A. (2000)

Note 1. Severe disability was defined as subnormal cognitive function, CP, blindness and/or deafness.

Note 2. These data were reported in a single study, therefore, a single percentage rather than a range was reported here.

Health Outcomes for Moderately-preterm Infants. An increasing number of studies indicate many of those infants who do not meet early intervention screening criteria initially because they are moderately-preterm or have a birth weight between 1,500 and 2,500 grams, are eventually discovered to have a developmental delay or qualifying condition prior to age 3. One such study, Kalia et al. (2009) found no significant difference in the rate at which moderately-preterm and very preterm infants qualified for early intervention services, after controlling for comorbidities such as the 5-minute Apgar score, receipt of caffeine for apnea of prematurity, bronchopulmonary dysplasia, respiratory distress syndrome, and length of stay. The researchers concluded "that late-preterm infants discharged from the NICU are at risk for developmental delays and should be screened for delays after hospital discharge" (p. 808). It is important to note that the infants in the moderately-preterm group and some in the very preterm infants group would not have qualified for referral to the Early Steps Program at birth due to a birth weight that exceeds the program's upper birth weight limit. The mean birth weight of the moderately-

preterm group was 2,192 grams (range = 1,808 to 2,576 grams.) The very preterm group had a mean birth weight of 1,114 grams (range = 740 to 1,484 grams).

Complications of Moderately-preterm Infants. Petrini et al. (2009) conducted a large-scale study of 142,735 infants born in Northern California of which 0.4% were very preterm and 5.3% were classified as moderately-preterm. They found moderately-preterm infants were three times more likely to be diagnosed with cerebral palsy when compared with term infants. The incidence of developmental delay or mental retardation was almost twice as high for moderately-preterm infants as for term infants (15.6 per 1,000 compared to 9.1 per 1,000 for term infants). Similarly, nearly twice as many moderately-preterm infants experienced seizures compared to term infants (2.3 per 1,000 versus 1.2 per 1,000). In their conclusion; Petrini et al. (2009, p. 175) state that "our results suggest that late preterm infants could benefit from neurological assessment and perhaps even developmental intervention. The large and growing number of late preterm infants substantiates the importance of understanding the implications of every additional gestational week for the developing child."

Engle et al. (2007) found that in the first 30 days of life, moderately-preterm infants are more likely to be readmitted to the hospital with jaundice, feeding difficulties, dehydration and suspected sepsis. Prior to discharge from the hospital at birth, "late-preterm infants are more likely than are term infants to be diagnosed with temperature instability, hypoglycemia, respiratory distress, apnea, jaundice, or feeding difficulties" (Engle et al., 2007, p. 1395).

Moderately-preterm Infants and Term Infants: Important Similarities and Implications for Referral Process Improvement. The lack of a widespread understanding of the risk of developmental delays in moderately-preterm infants may reflect the belief that moderately-preterm infants (especially those with a gestational age greater than or equal to 35 weeks) can be regarded as term infants. This assumption may contribute to lower referral rates or delayed referrals for moderately-preterm infants. Marks, Hix-Small, Clark and Newman (2009) studied referral patterns at a large multi-site pediatric practice in Oregon and found that when physicians and nurse practitioners relied on pediatric developmental impression, only 9.5% of the moderately-preterm infants they treated received referrals to early intervention services. Following the implementation of a universal, periodic Ages & Stages Questionnaire (ASQ) screening and surveillance system, referral rates for moderately-preterm infants rose to 26.2%. A much smaller increase was observed in referral rates for full-term infants. Prior to the use of the ASQ, the referral rate for full-term infants was 5.1%. When the ASQ was used for screening all infants, that rate increased to 8.1%.

According to Kalia et al. (2009, p. 807) these "late-preterm infants are often admitted to the newborn nursery and treated as term infants. They are not thought to be at greater risk than term infants for future medical or developmental disabilities." However, recent research has revealed that moderately-preterm infants differ from term infants on a range of health concerns (Wang, et al., 2004). These concerns include hypoglycemia, respiratory complications, apnea, feeding difficulties, prolonged hospital stays, and requiring readmission to the hospital after discharge.

The study's authors suggest these stressful conditions may contribute to poor developmental outcomes for these infants.

Another important factor that contributes to developmental delays found in many premature infants is the extent to which brain development has progressed at birth. Childs et al. (2001) produced a simple scoring system to assess cerebral maturation in preterm infants using four developmental parameters to produce a single maturation score. They examined the brain images of 134 healthy premature infants across a range of gestational ages from 23 to 41 weeks. Their findings revealed that 21.5% of brain maturity took place between the 39th week and the 41st week and that 38.5% of brain maturation occurred after the 35th week. (See Figure 2) While their study involved postnatal measurement of brain maturation, their results give a view into the timing of brain development prior to birth.

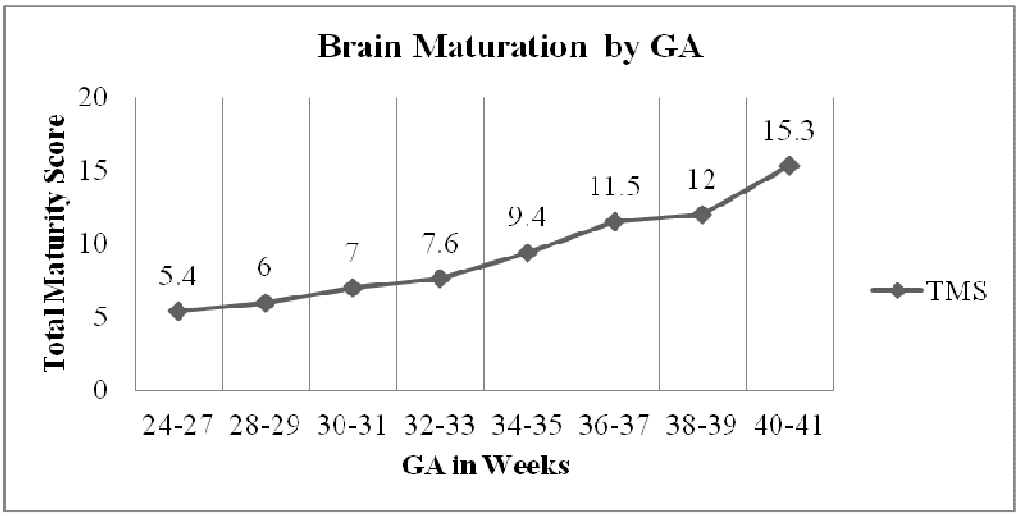

Figure 2. *Brain Maturation by Gestational Age*
Data from Childs, Ramenghi, Cornette, Tanner, Arthur, Martinez and Levene (2001).
Note. TMS is a composite of four parameters of brain growth.

Pietz et al. (2004) conducted a prospective long-term follow-up study of 70 carefully selected low-risk, low birth weight children who had presented no neurological impairment at birth. They followed these infants from birth to school-age and compared physical growth and cognitive performance in language development, visual perception, visual-motor integration and fine motor skills to a matched control group of 50 term infants with normal birth weight. The infants in the low birth weight sample were sorted into three subgroups by birth weight: 1,000 to 1,499 grams, 1,500 to 1,999 grams and 2,000 to 2,499 grams.

Data collected at the end of their study (when the subjects were approximately seven years old) revealed that the neuropsychological profile of the low-risk moderately-preterm children differed significantly from that of the control children. The statistical difference between the two groups was attributed to a higher proportion of moderately-preterm children with performance between one and two standard deviations below the mean, particularly in verbal skills. The differences between the moderately-preterm group and the control group were highly significant ($p > .001$) on two of the three sub-tests of verbal ability as well as on the sum of the verbal tests.

Interestingly, very few of the children in either group performed more than two standard deviations below the mean (one of 27 children in the 2,000 to 2,499 gram group and one of 50 in the control group.) In addition, a large proportion of the moderately-preterm children achieved normal levels of performance in all tested domains. Pietz et al. (2004, p. 141) concluded that “the differences between preterm and control observed in our study cannot be attributed to the inclusion of a small

group of children with a substantial handicap but rather represent a subtle shift of preterm's test results to the lower part of the normal distribution."

Pietz et al. (2004) summed up the implications of their findings with this recommendation:

> Since even preterm infants with low risk and a birth weight of 2000 to 2499 grams performed worse at 7 years in some domains (in particular verbal skills), all preterm infants should be included in a screening program to detect developmental abnormalities. Also those who show only subtle impairment during the early years of life should be followed at least until early school age. Early diagnosis of deficits will enable caretakers to begin treatment in time before the children start school. Considering the enormous costs of in-house hospital care for preterm infants, the relatively inexpensive follow-up care should be mandatory, and it should include also low-risk infants. (p. 142)

A Dutch study comparing moderately-preterm infants to term infants on a range of school-related measures found that 7.7% of the moderately-preterm children were enrolled in special education programs compared to only 2.8% of their age mates from the general population (van Baar, Vermaas, Knots, de Kleine & Soons, 2009). Moderately-preterm children in their study who attended regular education schools were retained for a second year in the same grade at a rate over twice as high as the children from the term group (8.8% versus 19%.) This difference was statistically significant ($\chi^2 = 9.45$; $p < 01$).

The two groups of children in van Baar et al. (2009) also differed on several data points collected through a survey of parents and teachers. Their teachers

reported greater attention deficits among the moderately-preterm group. The teachers' perceptions were supported by the results of a test designed to measure sustained attention. The test administered by the researchers showed that moderately-preterm children required more time to complete a series of tasks when compared to the performance of the term group. These results "showed a group difference in sustained attention to the disadvantage of the moderately preterm children, adjusted for maternal education" (van Baar, et al., 2009, p. 253).

Several studies cited in this paper have pointed to similar deficits in preterm infants who receive early intervention services and those who may not be screened for developmental delays because they weigh slightly more than the birth weight cutoff point included in the Early Steps Program eligibility criteria. These similarities argue for the extension of screening for early intervention services to the heavier low birth weight infants. An additional argument for providing screening babies born weighing between 1,200 and 2,500 grams is found in a follow-up study of the Infant Health and Development Program (McCormick et al, 2006). IHDP was a large-scale program of early intervention services at eight sites in states as diverse as New Jersey and Arkansas. The program provided weekly home visits for the first year and bi-weekly visits in the second and third years. Once participating infants reached 12 months of age, they were provided daily educational experiences at a local center until they turned three. Participants received intensive pediatric follow-up care and support groups were provided for their parents.

The McCormick study was designed to determine if improvements in cognitive and behavioral development documented in program participants at ages

five and eight would persist through adolescence. The original program (IHDP) divided participants into two birth weight categories: heavier low birth weight (HLBW; 2,001–2,499 grams) and lighter low birth weight (LLBW; <2,000 grams.) McCormick et al. (2006) found no significant differences in outcomes for infants in the intervention group and the control group who were born weighing less than 2,000 grams. However, for infants in the heavier low birth weight group (HLBW), statistically significant gains (p = .01) were made in reading and math achievement scores. Additional differences were found in favor of the HLBW group on the self-reporting of risky behaviors as measured by the Youth Risk Behavior Surveillance System and full scale IQ score on the Wechsler Abbreviated Scale of Intelligence. These differences were statistically significant, but at the .05 and .07 levels, respectively.

The authors note that participants in the LLBW groups did demonstrate gains from the intervention initially as documented by a difference of almost seven points in IQ scores at age three compared to the control group. However, this difference was no longer present by the time a second IQ score was obtained at age five. The level of participation was identified as a possible factor because those participants in the LLBW group who attended the daily center activities more than 400 days out of a possible 500 days during the intervention period maintained a slight edge over the control group on IQ scores.

Summary

When referral processes related to early intervention services are evaluated, the data collected and the analysis conducted typically focus on 1) the validity of the

outcomes of the process (to what extent are the initial referrals accurate in terms of identifying valid health and developmental issues), 2) the identification of undesirable delays in moving from one step to another in the process (how long do eligible infants and families wait for the next step in the process) and 3) the overall effectiveness of the process in identifying at risk infants and young children (what percentage of those who are likely to be at-risk were actually identified by the process).

Problem areas in various referral processes have been traced back to unnecessarily complex process designs, inadequate developmental surveillance and reliance on developmental impression rather than validated screening instruments (even though such instruments are readily accessible and have been used effectively by busy practices and service providers). These problem areas can result in delayed access to early intervention services for infants and families.

The serious health and developmental implications of pre-term birth and the increasing frequency of pre-term birth in the United States underscore the need for comprehensive developmental screening of even healthy-appearing infants who were only moderately pre-term as well as a referral process that is accessible, effective and efficient. If the referral process allows for excessive delays in accessing needed services, the outcomes for infants who experience delays will likely be poorer than they would have received if services had been provided promptly.

The findings of this literature review informed the evaluation of the Early Steps Program referral process as it is implemented in Hillsborough County, Florida

so that the evaluation focused on aspects of the referral process that determine prompt access to necessary services for eligible infants and families.

Chapter 3 Methodology/Design of the Study

How was the Referral Process Assessed?

To evaluate the extent to which the Early Steps referral process provides prompt access to early intervention services for eligible infants and their families, this study assessed the outcomes produced by this process in terms of the age at referral and the length of the wait from the date of referral to the date an Individual Family Services Plan or IFSP is completed. Age at referral is a measure of how long it takes within the Early Steps referral process for a developmental delay or condition that might lead to a developmental delay to be identified and the infant referred to Early Steps for evaluation. The length of time from the date of the initial referral to the date an IFSP is created provides a measure of the delay infants and families experience in waiting for services to begin following referral.

These two measures represent points within the referral process where delays in access to services occur and can be quantified through the data available from the Early Steps Program database. Potential sources of any delays that are detected can be identified by examining the association between a range of factors or variables and these two measures. When the likely sources of delayed access are identified, recommendations for improving prompt access can be made more precisely.

What Data was Collected and How was it Analyzed?

Outcome data analyzed for this study was obtained from the Florida Department of Health. The department is responsible for oversight of the Early Steps Database which

is housed in a secure system at the University of Florida Maternal Child Health and Education Research and Data Center (UF-MCHERDC). Upon approval of the research proposal, an application was submitted to the Institutional Review Board of the University of South Florida and to the Florida Department of Health. These applications detailed the specific uses of the data and the data format needed. Researchers at the UF-MCHERDC removed identifying information from the dataset and provided only the information that was necessary to complete the analysis.

As stated earlier, these data represent demographic and referral data for all infants referred to the Hillsborough County Early Steps Programs between January 1, 2006 and December 31, 2009. The data exist in a spreadsheet that includes 10,688 records. These data were originally collected on the Early Steps Demographic Form. This form is used statewide as an intake form. It contains fields for a wide range of demographic and program information and incorporates information from parent interviews as well as other sources such as hospital or physician records, where available.

Variables that were analyzed to determine possible sources of delays in prompt access included the following:

1. Referral date
2. Referral source
3. Age at referral in months
4. Reason for referral
5. Eligibility determination (reveals results of the Early Steps evaluation)
6. Barrier codes (identifies possible reasons for delays in completing an IFSP)
7. Initial IFSP date
8. Age in months at exit
9. Reason for exit

10. Gestational age
11. Maternal education
12. Gender
13. Race
14. County of birth
15. Medicaid eligibility

Research Questions and Hypotheses

The overarching research question was: What barriers to prompt access can be identified within the Early Steps referral process? This question follows from the hypothesis: If differences exist in key outcomes of the Early Steps referral process (i.e., age at referral and the duration of wait between referral and IFSP development) when analyzed by referral source and other relevant variables, then these differences may reveal points within the process where improvements in prompt access might be made.

Two additional tiers of more narrowly-focused research questions were necessary to obtain the answer to the broader question. These questions direct the analysis at key points within the referral process where delays may occur.

1) What factors are associated with age at referral to the Early Steps Program?

Answering this question involved creating a dichotomous variable to represent age at referral (those in the upper quartile in terms of age at referral vs. those in the lower quartiles) and using Chi–square tests of association to determine if an association exits between age at referral as a categorical outcome and referral source, reason for referral or any of the other factors listed in the previous section.

2) What factors are associated with the length of time from referral to the Early Steps Program to the completion of the IFSP?

This question was answered by using a dichotomous variable to represent the length of time from referral to IFSP (one group comprised of those who had an IFSP completed within the state's requirement of 45 days from referral and the second group made up of those who waited longer than 45 days for an IFSP to be completed). Chi–square tests of association were used to determine if an association exits between the length of time from referral to IFSP as a categorical outcome and referral source, reason for referral or any of the other variables drawn from the Early Steps demographic form.

Quantitative Analysis

Prior to answering the research questions, the data collected from the Early Steps Program were cleaned and made ready for appropriate analysis. Summaries of each original variable (referral date, referral source, age at referral, reason for referral, eligibility determination, barrier codes, initial IFSP date, age at exit, reason for exit, gestational age, maternal education, gender, race, county of birth and Medicaid eligibility) were generated. Categorical variables, which included all of the above except for age at referral, age at exit and gestational age, were summarized in contingency tables stratified by gender. Age at referral, age at exit and gestational age were summarized by median and interquartile range because they were determined by Shapiro–Wilk's test to be not normally distributed. All statistical analyses were performed through STATA version 9.

A list of the variables that were analyzed appears below. An asterisk identifies variables that are required fields on the Early Steps demographic form. Most of the categorical variables were collapsed into a smaller number of categories.

Where an explanation is needed, the rationale for this categorization is included below the description of the categories.

Variable 1: **Referral Source***

A) Physician
B) NICU
C) Community Agency/Provider
D) Self/Family
E) Other

Referral source categories were created by analyzing the percentage of referrals made by each source. Physicians, NICU staff, community agency or service provider staff and family members made 78.4% of all referrals made during the study period. The percentage of referrals from each of these four sources is relatively equal (physicians made the most at 21.7%; community agency/provider staff made the fewest at 15.6%). All other referral sources accounted for only 21.6% of referrals made, with none of the "other" sources making more than 6.2% of the total referrals made during the study period.

Variable 2: **Age at referral in months** (the original data are in days)*

Age at referral will be collapsed by recalculating the data from days to months. This change aligns the data with how most studies report data on this variable, i.e., in months rather than in days.

Variable 3: **Reason for Referral***

A) DD Speech,
B) DD at Risk,
C) DD Behavior,

D) DD Gross Motor
E) EC Sensory Unspecified,
F) EC Genetic/Metabolic,
G) EC Neurological,
H) EC Hearing, and
I) Other

This variable will be divided into 9 categories: Infants who were identified as having a delay in one of four DD domains, those who had an established condition that might lead to a developmental delay in one of four domains and those who were in other categories, not DD and not EC.

Variable 4: **Eligibility Determination**

A) DD Speech,
B) DD at Risk,
C) DD Behavior,
D) DD Gross Motor
E) EC Sensory Unspecified,
F) EC Genetic/Metabolic,
G) EC Neurological,
H) EC Hearing, and
I) Other

The same categories used for referral reason will be used for eligibility determination for consistency and to make potential comparisons possible.

Variable 5: **Barrier Codes**

A) Child/Family Issues
B) ES Capacity/Provider Issues
C) No Show/Unsuccessful Contact
D) Re-referred

Child and family issues were grouped to form a category because these reasons are closely related; likewise, issues arising from the Early Steps Program itself or service providers were combined because of the similarity in the roles of these groups. A third category was created by combining codes that reflect a loss of contact with the family. Those infants who were re-referred comprise the last category of barrier codes.

Variable 6: **Age in months at exit**

Variable 7: **Reason for exit**

A) Attempts to contact unsuccessful
B) Part B eligible, exiting Part C
C) Not eligible for ES services
D) Part B eligibility not determined
E) All other reasons

The data revealed that four categories of reasons for exit accounted for the majority (82%) of all records. All other reasons were grouped into one category.

Variable 8: **Gestational Age***

- Extremely Preterm - Less than 28 weeks
- Very Pre-term (28-32)
- Moderately Preterm (33-36)
- Term (37-42)

Variable 9: **Maternal Education***

A) Grade 1-8
B) Grade 9-12
C) HS Graduate
D) Partial College (2 year, 3 year, partial)
E) Bachelor's

F) Graduate (post master's and masters and PhD)

G) Unknown

This variable was categorized logically, making distinctions among mothers who finished middle school (but not high school), those who graduated from high school, those with some college education, those who earned a bachelor's degree and those who had completed some level of graduate study at the time they gave birth.

Variable 10: **Gender***

A) Male

B) Female

Variable 11: **Race***

A) White

B) Black

C) Hispanic

D) Other (includes Asian and Native Am)

E) Unknown

Variable 12: **County of Birth**

A) Hillsborough

B) Polk

C) Pasco

D) Manatee

E) Other

The full dataset included infants born in 33 of Florida's 67 counties. However, the number of infants from outside the West Central Florida area was typically less than 10 per county. The great majority came from the four counties used as individual categories, with over 7,000 of the 10,688 records indicating the infant was born in Hillsborough County.

Variable 13: **Medicaid Eligibility**

A) Yes
B) No

In addressing the first research question, the outcome variable was age at referral. Records were categorized into 2 groups (infants in the upper quartile of age at referral vs. those in the lower quartiles) and assigned values of 0 or 1. Chi–square tests of association were used to determine if an association exists between age at referral as a categorical outcome defined above and referral source as well as reasons for referral. In order to fully explore this outcome, all other variables were analyzed to determine if an association exists.

Categorical variables such as eligibility determination, barrier codes, gestational age, maternal education, gender, race, county of birth and Medicaid eligibility were each examined for association with age at referral using the Chi–square test of association. A Wilcoxon Rank–Sum test comparing the age at exit (in months) for the upper quartile of children based on age at referral to the age at exit for all others was conducted to determine if age at exit was associated with age at referral. This test was selected because the data were determined not to be normally distributed.

In order to quantify associations identified through the Chi-square tests, factors found to have a significant association were used to first build single predictor logistic regression models to calculate crude odds ratios. Then, multi-predictor models were built using both forward selection and backward stepwise selection. This 'full' model, i.e. the model containing all the explored covariates, was compared to at least one other multi–predictor model. Because the analysis was

interested particularly in referral source, a model including referral source, adjusting for reason for referral, was compared in the analysis to determine the most parsimonious model.

A similar approach was used to address the second research question. Time to IFSP was analyzed by creating two categories; infants who received services within 45 days of referral vs. those who waited longer than 45 days to begin services. The 45-day time constraint was selected to match the criteria in the Early Steps Program Handbook.

It is important to note that the data collected on the time to IFSP contained many blank fields. If the Early Steps assessment returns a finding that the child is not eligible for early intervention services, only the initial sections of the IFSP are completed. In these cases, the parent is given a copy of the completed sections and counseled on options that are available. No date is entered in the initial IFSP date field. Thus the records with no IFSP date belong to infants who were evaluated, but found to be ineligible for services through Early Steps. Such records were excluded from further analysis. It was assumed that the mechanism behind any other missing data was unrelated to any of the factors being explored and as such was treated as random.

Then, a Chi–square test of association was used to determine if time to IFSP as a categorical outcome defined above and referral source, as well as reasons for referral were associated. In order to fully explore this outcome, other factors were also examined to determine if an association exists.

Categorical variables such as eligibility determination, barrier codes, reason for exit, gestational age, maternal education, gender, race, county of birth and Medicaid eligibility were each examined for association with time to IFSP using the Chi–square test of association. A Wilcoxon Rank–Sum test was conducted to determine an association between age at exit and time to IFSP.

As described for question 1, a similar analysis to quantify any associations identified was conducted with the aim of finding the most parsimonious model which can be interpreted.

The process of identifying possible sources of delay involved the application of common statistical analyses and expert judgment. Therefore, the validity of the identification of sources of delay rests on the integrity of the original data and the ability of the researcher to interpret the output of the statistical analysis.

Summary

The search for aspects of the Early Steps Program referral process that can be modified to improve prompt access to early intervention services involved an exploration of the outcome data produced by the referral process. There are multiple points within the process where delays might occur. As examples, a pediatrician might adopt a "wait and see" approach relative to a concern expressed by a parent or an insufficient number of service providers may result in a longer wait for infants who need those specific services. The available data provide two sets of data points that reveal a range of wait-time durations. These are "age at referral" and "wait for IFSP."

These data points have significant variation. Age at referral varied from zero (date of referral = date of birth) to 35.7 months (an infant who was within a few weeks of the upper age limit for Part C). Wait for IFSP has a slightly narrower range, but one that still seems quite a bit wider than might be expected, particularly in light of the state's expectation that infants and families have a completed IFSP 45 days after referral. The longest wait for an IFSP was 1,033 days or approximately 34 months. The shortest wait was zero, meaning that the IFSP was created on the same day the referral was made.

It is important to note that while the ranges are large for both measures of delay in access to services (Age at Referral and Time to IFSP); the number of valid records for each measure is not. All of the 10,688 records have a valid age at referral because all of the records have both a date of birth and date of referral. However, only 5,396 records have valid dates for the creation of the IFSP. Seventy-three records had an IFSP date that was prior to the referral date and as such are likely to be the result of inaccurate data entry. In addition, there are 5,220 records that have no IFSP date. These records indicate the infant was evaluated, but found to be ineligible for services through Early Steps. Only records with a valid IFSP date were included in this phase of the data analysis.

The research questions focused on identifying factors that are associated with delays in prompt access as measured by Age at Referral and Time to IFSP. Where such associations were found, further analysis was conducted to quantify the association to provide estimates of the influence of the variable on the delay. The researcher used these analyses to target specific aspects of the referral process for improvement and generate recommendations for interventions and changes in the process that are intended to

shorten the wait for referral and for the completion of an IFSP that allows infants and families faster access to needed services.

Chapter 4 Results

Summary of Purpose and Methodology

The purpose of this study was to determine the existence of barriers to prompt access to early intervention services in the Early Steps referral process so that efforts to make the process more efficient and effective could be targeted more precisely. Focusing the work of generating recommendations through this type of analysis increases the likelihood the study's recommendations will produce improved levels of prompt access to early intervention services. This, in turn, should help infants and their families experience better outcomes and reduce the costs of intervention services required after the age of 3 because developmental concerns were identified and treated earlier.

The dataset included demographic and referral information for all infants referred to the Hillsborough County Early Steps Programs between January 1, 2006 and December 31, 2009. These data were stored at the University of Florida Maternal Child Health and Education Research and Data Center. The Early Steps Demographic Form, a statewide intake form, was used to collect information from parent interviews and other sources such as hospital or physician records. Data are entered on the form by an intake coordinator employed and trained by Early Steps. Overall, the dataset included 10,688 records.

The dataset allowed the researcher to identify two measures of delays in access to early intervention services: age at referral and the time from referral to the development of an IFSP. The variable, *Age at Referral*, measures the time required within the Early

Steps referral process for a developmental delay or condition that might lead to a developmental delay to be identified and the infant referred to Early Steps for an initial assessment. The time from the date of the initial referral to the date an IFSP is created, *Time to IFSP*, is a measure of the delay infants and families experience in waiting for services to begin following referral.

These two measures represent points within the referral process where delays in access to services occur and can be quantified through the available data. Delays were detected in both measures. Potential sources of these delays were identified by examining the association between a set of variables from the dataset and these two measures. Once the strength of those associations had been determined, hypotheses were drawn about how those delays occurred and recommendations for addressing them were generated.

Findings

Descriptive Statistics. Descriptive statistics that provide preliminary insights into the dataset are summarized in tables 5 through 8. Numerical variables are summarized in total and across gender in Table 5. These variables were found to be other than normally-distributed and hence are reported by medians and interquartile ranges. Findings of note relative to gender include the disproportionate number of males in the study population (61.9%) and the difference in age at referral (females were almost 8 months younger at referral).

The Early Steps Program serves infants age 0 to 3, but the dataset included a number of outliers in terms of age. There were 1,320 infants who had an age at exit that was greater than 36 months and 6 of the total 10,688 records included an age at referral greater than 36 months. It is likely that the 6 with an age at referral greater than 36

months were data entry errors. However, the infants who appear to have remained in the program beyond their third birthday are more likely to be cases in which it was deemed important to continue to provide services beyond the cutoff age.

Table 5. *Summary Statistics across Gender*

Variable	N	Minimum	Maximum	Median	IQR
Age at Referral (in months)	10,688	0	49.8	17.6	23.4
Male	6,617	0	37.2	19.6	22.2
Female	4,071	0	49.8	11.8	23.0
Age at Exit (in months)	9,645	0.03	51.7	29.0	22.4
Male	6,015	0.07	46.8	31.5	18.5
Female	3,630	0.03	51.7	24.4	26.0
missing	1043				
Gestational Age (in weeks)	10,688	20	45	40	4
Male	6,617	20	45	40	4
Female	4,071	22	45	40	6
Time to IFSP* (in days)	5,395	0	1,048	43	48
Male	3,538	0	1,048	42	42
Female	1,857	0	1,015	44	58

*Includes NICU babies

Four referral sources accounted for almost 80% of the referrals to the Early Steps Program during the study period; while the other 10 referral sources made from 0.4% to 6.17% of the referrals. Therefore, all referral sources other than the four most common were collapsed into one category. These sources are identified, along with the number and percentage of the total referrals made by each source, in Table 6.

Table 6. *Most Common Referral Sources, Number and Percentage of Referrals*

Referral Source	Number of Referrals Made	Percentage of Total Referrals in Sample
Physician	2,322	21.7%
NICU	2,215	20.7%
Self/Family	2,150	20.1%
Community Agency/Provider	1,671	15.6%
All Other Sources	2,330	21.8%
Totals	10,688	100.0%

Table 7 displays the breakdown of three key variables (referral source, referral reason and eligibility determination) by gender. Two interesting observations can be made concerning referral source. One is that the percentages of referrals from the four categories that are made up of individual sources are roughly equal to the percentage referred from all other sources combined (approximately 20%). Also, there is little variation within each source in terms of gender (males and females are referred at approximately the same rate by each source) except for referrals from the NICU. The difference in the rate at which female infants are referred from the NICU compared to male infants is somewhat larger than might be expected.

Thirty-eight percent (4,067) of the records in the dataset were missing data on the eligibility determination code. This data was missing from the Early Steps Demographic form if an infant failed to meet the eligibility criteria or if the field was left blank. (Eligibility Determination is not a required field.) Of those that were coded for eligibility, 50.7% were referred to the Early Steps Program with the referral reason of DD At Risk; a “catch-all” category used when no specific

diagnosis of developmental delay is made at the time of referral. However, the most common eligibility determination code was DD Speech (43.2%). For all of the referral reasons except DD Speech and DD At Risk (the two most frequently used codes) there is little difference in referral rates between male and female infants. Females were more likely than males to be referred for DD At Risk and males were more likely to be referred for DD Speech. This pattern surfaced in eligibility determination as well, with the higher rate for DD Speech for males appearing even more pronounced in eligibility determination than it was in referral reason.

Table 7. *Referral Source, Referral Reason and Eligibility Determination by Gender*

Variable	Male	Female	Total
Referral Source			
Physician	22.6%	20.2%	21.7%
NICU	17.3%	26.3%	20.7%
Self/Family	21.5%	17.9%	20.1%
Community Agency/Provider	16.9%	13.5%	15.6%
All Other Referral Sources	21.6%	22.1%	21.8%
N	6,617	4,071	10,688
Referral Reason			
DD Speech	26.4%	17.1%	22.9%
DD At Risk	48.3%	54.4%	50.7%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	1.7%	1.1%	1.5%
DD Gross Motor	3.2%	4.7%	3.8%
EC Sensory Unspecified.	0.0%	0.0%	0.0%
EC Genetic/Metabolic	1.3%	2.1%	1.6%
EC Neurological	0.9%	1.4%	1.1%
EC Hearing	1.1%	1.4%	1.2%
All Other Referral Reasons	17.0%	17.7%	17.3%
N	6,617	4,071	10,688
Eligibility Determination			
DD Speech	31.1%	19.7%	26.8%
DD At Risk	12.2%	15.0%	13.2%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	1.0%	0.7%	0.9%

Variable	Male	Female	Total
DD Gross Motor	3.9%	5.1%	4.4%
EC Sensory Unspecified.	0.0%	0.0%	0.0%
EC Genetic/Metabolic	1.7%	3.0%	2.2%
EC Neurological	1.5%	2.6%	1.9%
EC Hearing	1.1%	1.4%	1.2%
All Other Eligibility Codes	10.9%	11.3%	10.5%
Missing	36.6%	12.2%	11.4%
N	6,617	4,071	10,688

Not surprisingly, the distribution of barrier codes was similar for male and female infants, including the 5,767 records that were missing barrier code information. The majority of the infants were classified as full-term or at least 37 weeks gestation (these data were parent-reported). Maternal education was largely recorded as "unknown" (57.3%), but 14.1% had completed high school.

Table 8. *Barrier Codes, Reason for Exit, Gestational Age and Maternal Education by Gender*

Variable	Male	Female	Total
Barrier Codes			
Child/Family Issues	24.5%	27.9%	25.8%
ES Capacity/Provider Issues	3.5%	3.4%	3.5%
No Show/Unsuccessful Contact	10.6%	10.2%	10.5%
Re-referred	6.3%	6.3%	6.3%
Missing	55.1%	52.1%	54.0%
N	6,617	4,071	10,688
Reason for Exit			
Attempts to Contact Unsuccessful	15.2%	18.3%	16.4%
Part B Eligible, Exiting C	19.2%	12.7%	16.7%
Not ES Eligible	17.9%	20.1%	18.7%
Part B Not Determined	11.1%	7.3%	9.6%
Other	27.6%	30.8%	28.8%
Missing	9.1%	10.8%	9.8%
N	6,617	4,071	10,688
Gestational Age (in weeks)			
< 28	4.2%	7.1%	5.3%
28 - 32	10.5%	15.1%	12.2%
33 - 36	10.5%	11.7%	11.0%

Variable		Male	Female	Total
	37+	74.8%	66.1%	71.5%
	N	6,617	4,071	10,688
Maternal Education				
	Grades 1 - 8	3.3%	3.5%	3.4%
	Grades 9 - 12	4.7%	5.9%	5.1%
	High School Graduate	14.4%	13.5%	14.1%
	Partial College	9.4%	8.8%	9.2%
	Bachelor's Degree	8.1%	7.0%	7.7%
	Graduate Work	3.5%	2.9%	3.3%
	Unknown	56.6%	58.3%	57.3%
	N	6,617	4,071	10,688

Medicaid status was active for almost 60% of the entire study population; however, the distribution across gender shows a slight imbalance with 62.1% of females and 57.9% of males having active Medicaid status. Two-thirds of infants (66.6%) who were referred for early intervention services in the Hillsborough County Early Steps catchment area were born in Hillsborough County.

Table 9. *Race, County of Birth and Medicaid Status by Gender*

Variable		Male	Female	Total
Race				
	Black	15.0%	17.2%	15.9%
	White	44.2%	41.3%	43.1%
	Hispanic	23.2%	22.4%	22.9%
	Other	3.0%	3.2%	3.1%
	Unknown	14.6%	15.8%	15.1%
	N	6,617	4,071	10,688
County of Birth				
	Hillsborough	67.9%	64.5%	66.6%
	Polk	25.5%	28.4%	26.6%
	Pasco	1.2%	1.6%	1.4%
	Manatee	2.4%	2.3%	2.4%
	All Other Counties	3.0%	3.2%	3.1%
	N	6,617	4,071	10,688
Medicaid Active?				
	NO	42.1%	37.9%	40.5%

Variable		Male	Female	Total
	YES	57.9%	62.1%	59.5%
	N	6,617	4,071	10,688

Statistical Analysis

The initial phase of data analysis focused on research question 1: What factors are associated with age at referral to the Early Steps Program? The 10,688 records within the dataset were assigned to one of two groups; Group A, which included infants who were in the upper quartile in terms of age at referral, and Group B, infants who were in the lower three quartiles of age at referral. The Rank Sums test found significant differences between Groups A and B on each of three variables: Age at Exit, Gestational Age and Time to IFSP.

Table 10. *Rank Sums test for Age at Exit, Gestational Age and Time to IFSP*

Variable		N	Min	Max	Median	IQR	p – value
Age at Exit (months)	All	9645	0.03	51.7	29.0	22.4	
	Group A	2,661	26.3	51.7	35.9	3.2	< 0.001
	Group B	6,984	0.0	41.8	21.6	26.9	
	Missing	1,043					
Gestational Age (weeks)	All	10,688	20	45	40.0	4.0	
	Group A	2,666	23	45	40.0	0.0	< 0.001
	Group B	8,022	20	45	39.0	7.0	
Time to IFSP (days)	All	5,395	0	1,048	43.0	48.0	
	Group A	1,433	0	258	37.0	27.0	< 0.001
	Group B	3,962	0	1,048	45.0	67.0	

The results of Pearson's chi-square tests of association for each categorical variable with age at referral are summarized in Tables 11 through 13. These results reveal an association between each of the variables and age at referral. This

association for all variables, with the exception of Medicaid status and Maternal Education, was significant at the 0.001 level.

Table 11. *Chi-square Tests of Association for Referral Source, Referral Reason and Eligibility Determination for Groups A and B*

Variable	Group A	Group B	Total
Referral Source ***			
Physician	19.0%	22.6%	21.7%
NICU	0.3%	27.5%	20.7%
Self/Family	28.2%	17.4%	20.1%
Community Agency/Provider	24.3%	12.8%	15.6%
All Other Referral Sources	28.2%	19.7%	21.8%
N	2,666	8,022	10,688
Referral Reason ***			
DD Speech	41.3%	16.8%	22.9%
DD At Risk	35.8%	55.6%	50.7%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	2.7%	1.1%	1.5%
DD Gross Motor	0.8%	4.8%	3.8%
EC Sensory Unspecified.	0.0%	0.0%	0.0%
EC Genetic/Metabolic	0.7%	1.9%	1.6%
EC Neurological	0.4%	1.3%	1.1%
EC Hearing	0.3%	1.6%	1.2%
All Other Referral Reasons	18.0%	17.0%	17.3%
N	2,666	8,022	10,688
Eligibility Determination ***			
DD Speech	40.5%	22.2%	26.8%
DD At Risk	3.8%	16.3%	13.2%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	1.5%	0.7%	0.9%
DD Gross Motor	0.3%	5.7%	4.4%
EC Sensory Unspecified.	0.0%	0.0%	0.0%
EC Genetic/Metabolic	0.6%	2.7%	2.2%
EC Neurological	0.3%	2.4%	1.9%
EC Hearing	0.3%	1.5%	1.2%
All Other Eligibility Codes	11.1%	11.5%	11.4%
Missing	41.7%	36.8%	38.1%
N	2,666	8,022	10,688

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

Table 12. *Chi-square Tests of Association for Barrier Codes, Reason for Exit, Gestational Age and Maternal Education for Groups A and B*

Variable	Group A	Group B	Total
Barrier Codes ***			
Child/Family Issues	14.8%	29.4%	25.8%
ES Capacity/Provider Issues	3.4%	3.5%	3.5%
No Show/Unsuccessful Contact	10.7%	10.4%	10.5%
Re-referred	1.8%	7.8%	6.3%
Missing	69.3%	48.9%	54.0%
N	2,666	8,022	10,688
Reason for Exit ***			
Attempts to Contact Unsuccessful	12.4%	17.7%	16.4%
Part B Eligible, Exiting C	32.4%	11.5%	16.7%
Not ES Eligible	21.7%	17.7%	18.7%
Part B Not Determined	15.5%	7.7%	9.6%
Other	17.8%	32.5%	28.8%
Missing	0.2%	12.9%	9.8%
N	2,666	8,022	10,688
Gestational Age (weeks) ***			
< 28	0.6%	6.9%	5.3%
28 - 32	1.5%	15.8%	12.2%
33 - 36	6.0%	12.7%	11.0%
37+	92.0%	64.7%	71.5%
N	2,666	8,022	10,688
Maternal Education **			
Grades 1 - 8	3.4%	3.4%	3.4%
Grades 9 - 12	4.3%	5.4%	5.1%
High School Graduate	14.5%	13.9%	14.1%
Partial College	11.3%	8.5%	9.2%
Bachelor's Degree	7.2%	7.8%	7.7%
Graduate Work	3.2%	3.3%	3.3%
Unknown	56.1%	57.7%	57.3%
N	2,666	8,022	10,688

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

Table 13. *Chi-square Tests of Association for Gender, Race, County of Birth and Medicaid Status for Groups A and B*

Variable		Group A	Group B	Total
Gender ***				
	Male	70.3%	59.1%	61.9%
	Female	29.7%	40.9%	38.1%
	N	2,666	8,022	10,688
Race ***				
	Black	14.1%	16.4%	15.9%
	White	39.9%	44.1%	43.1%
	Hispanic	24.8%	22.3%	22.9%
	Other	3.5%	2.9%	3.1%
	Unknown	17.7%	14.2%	15.1%
	N	2,666	8,022	10,688
County ***				
	Hillsborough	72.2%	64.8%	66.6%
	Polk	23.8%	27.5%	26.6%
	Pasco	0.5%	1.7%	1.4%
	Manatee	2.0%	2.5%	2.4%
	All Other Counties	1.5%	3.6%	3.1%
	N	2,666	8,022	10,688
Medicaid Active *				
	NO	42.4%	39.8%	40.5%
	YES	57.6%	60.2%	59.5%
	N	2,666	8,022	10,688

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

Single predictor logistic regression models were built to calculate the unadjusted odds ratios for each variable of interest to quantify the associations found through the Chi-square tests. Tables 14 through 17 summarize the results of these regression models. Not surprisingly, being older at exit was associated with increased odds of being older at referral. The Early Steps Program serves infants 0 to 3 years of age and therefore, infants who are closer to their third birthday when they are referred to the program are likely to be older at exit.

Gestational age is also associated with being older at referral. For each additional week in gestational age, a child had 23% increased odds of being among the upper quartile of age at referral (i.e., being in group A). One possible explanation for this finding is that infants who are full-term typically have fewer of the health concerns associated with premature birth and so, developmental delays or other relevant conditions may appear later for these infants.

Table 14. *Unadjusted Odds Ratios: Age at Exit, Gestational Age and Time to IFSP*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Age at Exit (months)	1.22	< 0.001	1.20	1.23
Gestational Age (weeks)	1.23	< 0.001	1.21	1.25
Time to IFSP (days)	0.99	< 0.001	0.99	0.99

Also not surprising is the fact that being referred from the NICU compared with being referred by a physician was associated with decreased odds of being older at referral (i.e., decreased odds of being in group A). Infants referred from the NICU in Groups A and B (for all referral reasons) had a mean age at referral of just less than one month compared to a mean age at referral of 16.4 months for all referral sources, including the NICU. While children referred from Community Agency/Providers, Self/Family and Other Sources were almost twice as likely to be in group A (older at referral) as were children referred by Physicians.

All referral reasons with the exception of DD Behavior, were associated with reduced odds of being older at referral when compared with DD Speech, while being referred for DD Behavior was associated with slightly increased odds of being older at referral when compared with DD Speech, although this result was not significant.

Table 15. *Unadjusted Odds Ratios: Referral Source, Referral Reason and Eligibility Determination*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Referral Source - (reference - physician)				
NICU	0.01	< 0.001	0.01	0.03
CAP	1.93	< 0.001	1.69	2.20
Self/Family	2.27	< 0.001	1.98	2.61
Other	1.71	< 0.001	1.50	1.95
Referral Reason - (reference DD Speech)				
DD At Risk	0.26	< 0.001	0.24	0.29
DD Behavior	1.03	0.879	0.74	1.41
DD Gross Motor	0.07	< 0.001	0.04	0.10
EC Genetic/Metabolic	0.15	< 0.001	0.09	0.24
EC Neurological	0.12	< 0.001	0.06	0.22
EC Hearing	0.08	< 0.001	0.04	0.16
Other	0.43	< 0.001	0.38	0.49
Eligibility Determination - (reference DD Speech)				
DD At Risk	0.13	< 0.001	0.10	0.16
DD Behavior	1.17	0.458	0.77	1.78
DD Gross Motor	0.03	< 0.001	0.02	0.06
EC Sensory Unspecified	1.65	0.723	0.10	26.43
EC Genetic/Metabolic	0.11	< 0.001	0.07	0.19
EC Neurological	0.07	< 0.001	0.03	0.14
EC Hearing	0.10	< 0.001	0.04	0.21
Other	0.53	< 0.001	0.45	0.61

Three categories of barrier codes were compared to the barrier code Child/Family Issues in terms of association with age at referral. Infants and families who were coded with either ES Capacity/Provider Issues or No Show/Unsuccessful Contact were almost twice as likely to be older at referral when compared to those whose indicated barrier code was Child/Family Issues. The reverse is true for infants who were coded as Re – referred when compared to those with Child/Family Issues. That is, infants coded as Re-referred were only half as likely to be older at referral as those with Child/Family Issues.

Older gestational age was also associated with older age at referral. Although maternal education did show a significant association with age at referral; the unadjusted odds ratios did not produce any significant ratios.

Table 16. *Unadjusted Odds Ratios: Barrier Codes, Reasons for Exit, Gestational Age and Maternal Education*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Barrier Codes - (reference - Child/Family Issues)				
ES Capacity/Provider Issues	1.93	< 0.001	1.48	2.50
No Show/Unsuccessful Contact	2.04	< 0.001	1.72	2.43
Re - Referral	0.47	< 0.001	0.34	0.64
Reasons for Exit - (reference - Attempts to Contact Unsuccessful)				
Part B Eligible, Exiting Part C	4.04	< 0.001	3.47	4.70
Not Eligible For ES	1.74	< 0.001	1.50	2.04
Part B Eligibility Not Determined.	2.86	< 0.001	2.41	3.40
Other Reasons	0.78	0.002	0.67	0.91
Gestational Age (weeks) - (reference 37+ weeks)				
< 28 weeks	0.06	< 0.001	0.03	0.10
28 - 32	0.06	< 0.001	0.05	0.09
33 - 36	0.33	< 0.001	0.28	0.40
Maternal Education - (reference - Grades 1 - 8)				
Grades 9 - 12	0.78	0.124	0.57	1.07
High School Graduate	1.02	0.869	0.78	1.33
Partial College	1.30	0.057	0.99	1.71
Bachelor's Degree	0.91	0.512	0.68	1.21
Graduate	0.96	0.794	0.68	1.34
Unknown	0.95	0.712	0.75	1.22

Females had reduced odds of being in the older quartile at referral. There was no significant difference in the odds of being older at referral for White children when compared to Black children. However, Hispanic, other and unknown races were more likely than their Black counterparts to be older at referral. Children from all other counties were less likely to be older at referral than children from Hillsborough County, possibly indicating that distance is not a barrier to prompt access. Medicaid status also was able to predict age at referral. Children whose

Medicaid status was active were less likely to be older at referral than those with an inactive Medicaid status.

Table 17. *Unadjusted Odds Ratios: Gender, Race, County of Birth and Medicaid Status*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Gender				
Females vs. Males	0.61	< 0.001	0.56	0.67
Race - (reference - Black)				
White	1.05	0.456	0.92	1.20
Hispanic	1.29	0.001	1.12	1.49
Other	1.37	0.021	1.05	1.79
Unknown	1.44	< 0.001	1.23	1.69
County - (reference - Hillsborough)				
Polk	0.78	< 0.001	0.70	0.86
Pasco	0.28	< 0.001	0.16	0.49
Manatee	0.70	0.025	0.51	0.96
other	0.39	< 0.001	0.28	0.54
Medicaid				
Active vs. Inactive	0.90	0.017	0.82	0.98

Multivariable Model 1/Age at Referral (All Predictor Variables). A logistic regression model was built using all of the predictor variables (Multivariable Model 1). The summary of these results are shown in Tables 18 through 20. Quite interestingly, in the presence of other variables, gestational age, maternal education, gender, race, county of birth and Medicaid status were no longer able to significantly predict age at referral.

Table 18. *Adjusted Odds Ratios: Referral Source, Referral Reason and Eligibility Determination*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Referral Source - (reference - Physician)				
NICU	0.11	0.001	0.03	0.41
Community Agency/Provider	1.80	0.001	1.27	2.57
Self/Family	2.68	< 0.001	1.86	3.86
Other	2.36	< 0.001	1.66	3.36
Referral Reason - (reference DD Speech)				
DD At Risk	1.01	0.958	0.75	1.36
DD Behavior	0.40	0.07	0.15	1.08
DD Gross Motor	0.11	0.005	0.02	0.51
EC Genetic/Metabolic	0.67	0.52	0.20	2.26
EC Neurological	0.75	0.827	0.06	9.79
EC Hearing	0.17	0.132	0.02	1.69
Other	0.58	0.005	0.39	0.84
Eligibility Determination - (reference DD Speech)				
DD At Risk	0.78	0.287	0.49	1.24
DD Behavior	1.24	0.619	0.53	2.94
DD Gross Motor	0.03	0.001	0.00	0.25
EC Genetic/Metabolic	0.38	0.09	0.12	1.16
EC Neurological	0.15	0.041	0.02	0.93
EC Hearing	0.09	0.033	0.01	0.83
Other	1.02	0.891	0.73	1.44

*Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age, maternal education, gender, race, county and Medicaid status.

Table 19. *Adjusted Odds Ratios: Barrier Codes, Reasons for Exit, Gestational Age and Maternal Education*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Barrier Codes - (reference - Child/Family Issues)				
ES Capacity/Provider Issues	0.62	0.01	0.43	0.89
No Show/Unsuccessful Contact	1.31	0.105	0.95	1.81
Re - Referral	0.24	< 0.001	0.16	0.36
Age at Exit				
Each Additional Month	1.39	< 0.001	1.29	1.51
Reasons for Exit - (reference - Attempt to Contact Unsuccessful)				
Part B Eligible, Exiting Part C	0.84	0.546	0.49	1.46
Not Eligible For ES	4.33	< 0.001	1.94	9.65
Part B Eligibility Not Determined	0.57	0.052	0.32	1.00

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Other Reasons	0.50	0.017	0.28	0.88
Gestational Age (weeks) - (reference 37+ weeks)				
< 28 weeks	0.46	0.003	0.28	0.76
28 - 32	0.54	0.123	0.25	1.18
33 - 36	0.46	0.243	0.12	1.70
Maternal Education - (reference - Grades 1 - 8)				
Grades 9 - 12	1.05	0.9	0.50	2.20
High School Graduate	0.97	0.934	0.50	1.90
Partial College	0.84	0.624	0.42	1.69
Bachelor's Degree	0.47	0.06	0.22	1.03
Graduate	0.50	0.145	0.19	1.27
Unknown	0.93	0.825	0.50	1.74

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age, maternal education, gender, race, county and Medicaid status.

Table 20. *Adjusted Odds Ratios: Gender, Race, County of Birth and Medicaid Status*

Group A vs. B	Odds Ratio	P - value	[95% Conf. Interval]	
Gender				
Females vs. Males	1.13	0.38	0.86	1.50
Race - (reference - Black)				
White	1.12	0.564	0.76	1.64
Hispanic	0.81	0.303	0.55	1.21
Other	1.45	0.261	0.76	2.79
Unknown	0.89	0.634	0.56	1.42
County - (reference - Hillsborough)				
Polk	1.01	0.964	0.74	1.37
Pasco	1.00	0.999	0.04	28.03
Manatee	8.43	0.378	0.07	963.27
Other	1.68	0.496	0.38	7.50
Medicaid				
Active vs. Inactive	0.88	0.396	0.65	1.19

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age, maternal education, gender, race, county and Medicaid status.

Multivariable Model 2/Age at Referral. Model 2 was generated by backward stepwise elimination using an entry p – value of 0.005 and a removal p – value of 0.01. The model produced was not surprising as it included the variables from model

1 which predicted the outcome and removed those that did not. When all variables were present, maternal education, gender, race, county of birth and Medicaid status were no longer able to significantly predict age at referral and therefore, were not included in Model 2.

Identifying those variables associated with being older at the time of referral with a high level of confidence should provide clues to sources of delay in referral for early intervention services. Based on the results of Model 2, the variables with the greatest influence on age at referral were referral source, referral reason, barrier codes, age at exit, reasons for exit and gestational age. Findings related to each of these variables, along with summary data in Tables 21 through 24, are presented below.

Referral Source. Table 21 displays the results of a logistic regression model analysis of these referral sources using Physician as the reference. These data show that referrals from the NICU and those made by physicians were more likely to be in Group B (younger at referral) while referrals from the other sources were more likely to be in Group A.

Table 21. *Likelihood of Referral Source Predicting Age at Referral*

Group A vs. B	Adjusted* Odds Ratio	P – value**	[95% Conf. Interval]	
Referral Source - (reference - Physician)				
NICU	0.11	0.001	0.03	0.41
Community Agency/Provider	1.80	0.001	1.27	2.57
Self/Family	2.68	< 0.001	1.86	3.86
Other	2.36	< 0.001	1.66	3.36

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.005, Removal P – value = 0.010)

Newborns are transferred to the NICU because there is an immediate problem. Because these developmental or other health concerns are recognized at birth or at least

prior to discharge, these infants are more likely to be referred for early intervention services within a short time after they are born. Therefore, it is logical that these infants would be younger at the time of referral. Infants referred by physicians were also more likely to be younger at referral. This supports a conclusion that physicians within the study area are making referrals in a timely manner and therefore, contribute to more prompt access to early intervention services.

Infants referred to Early Steps by Self/Family, Community Agency/Provider and Other Sources were generally older at referral. There are several possible explanations. Some pediatricians take a "wait and watch" approach to signs of developmental delay or to concerns expressed by parents or the pediatrician may miss early cues to a problem. This can leave parents less anxious about their concern since they have been given some level of reassurance by the doctor or healthcare professional. In these situations, parents or family members may wait to make a self-referral until developmental problems become more pronounced or they hear an observation or opinion from a more experienced parent or healthcare professional suggesting that a problem might indeed exist. Also, young babies are less likely to be seen by a Community Agency/Provider such as the Early Childhood Council or a local daycare provider until there is a delay that is more obvious.

Referral Reason. Two referral reasons were associated with being older at referral: DD Speech and DD At Risk. Because the developmental milestones for speech are later than those of other referral reasons, it was expected that concerns that might result in referral for speech services would arise when the child was older relative to concerns associated with other referral reasons such as gross motor

development or hearing. That DD At Risk would be associated with a longer wait for referral was at first counterintuitive because a large percentage (37.3%) of the DD At Risk referrals in the dataset were made from the NICU. A closer look at age at referral for infants from the entire study population who were coded DD At Risk revealed that infants referred with this code by NICU staff had a mean age at referral of 21.6 days compared to a mean age of 549 days for those coded as DD At Risk by all other sources. Thus, the basis for the influence of this referral reason on age at referral came exclusively from these other sources. One possible explanation for this finding is how referral sources other than the NICU use the DD At Risk code. This referral code is used when a general concern is identified; one that is likely to be less severe or readily observable compared to reasons such as hearing impairment or gross motor delays (reasons that were 6 to 8 times more likely to be used with children who were younger at referral). Shevell, Majnemer, Rosenbaum and Abrahamowicz (2001) conducted a study to search for patterns of referral to subspecialty clinics for young children with suspected developmental delay and to identify the factors prompting their referral. Referring physicians were asked to rank the following factors in order of importance in prompting referrals for specialty evaluation of a child with an observable developmental delay: age of the child, severity of the delay, parental insistence, suspected etiology and provision of rehabilitation services. They found that for the referring physicians in their study, the major factor prompting referral was the severity of the observed delay. This may provide a partial explanation for the finding that children referred with the referral reason of DD At Risk were likely to be older at the time of referral compared to

children with more specific diagnoses. If the referral sources in the present study adhere to the same pattern as those in the Shevell et al. study, they may have been more likely to wait longer to refer a child if the concern was more general in nature and DD At Risk was appropriate. Table 22 provides odds ratios for membership in Group A for each referral reason compared to DD Speech.

Table 22. *Likelihood of Referral Reason Predicting Age at Referral*

Group A vs. B	Adjusted* Odds Ratio	P – value**	[95% Conf. Interval]	
Referral Reason - (reference – DD Speech)				
DD At Risk	1.01	0.961	0.75	1.35
DD Behavior	0.42	0.083	0.15	1.12
DD Gross Motor	0.12	0.006	0.03	0.55
EC Genetic/Metabolic	0.67	0.508	0.20	2.20
EC Neurological	0.71	0.798	0.05	9.75
EC Hearing	0.16	0.114	0.02	1.55
Other	0.60	0.008	0.42	0.88

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.005, Removal P – value = 0.010)

Barrier Codes. These codes represent reasons for delays in completing the tasks necessary for developing an Individual Family Services Plan or IFSP. As such, they are important sources of information about possible delays in accessing services through the Early Steps Program. Two categories of barrier codes predicted being older at referral. These were Child/Family Issues and No Show/Unsuccessful Contact. Child/Family issues include things such as illness, appointment conflicts and transportation. Unreturned phone calls, disconnected phone or being unable to locate the family are examples of No Show/Unsuccessful Contact.

No studies were found that directly addressed the impact of behaviors associated with the barrier codes of Child/Family Issues and No Show/Unsuccessful Contact on the process of referral for early intervention services. However, much of what has been

studied relative to missing doctor or clinic appointments can be generalized to the referral process and therefore, may provide an explanation for this finding. For example, in a study of patient perceptions of why clinic appointments are missed without notifying the provider, participants identified 3 types of issues: anxiety over the possibility of receiving a negative diagnosis or prognosis, a perceived lack of respect from provider staff and an incomplete or inaccurate understanding of the scheduling system and the impact of missing an appointment (Lacy, Paulman, Reuter & Lovejoy, 2004). Patients who were interviewed for the Lacy et al. study mentioned logistical issues such as transportation and childcare, but did not identify these challenges as key reasons for missing appointments. For these participants, making an appointment with the clinic was driven by immediate symptoms and a desire to obtain treatment. At the same time, many of them described experiencing anticipatory fear and anxiety about painful procedures and getting bad news, i.e., fear of injections or a diagnosis of serious illness. If the wait time for an appointment allowed for a lessening of the symptoms over time, many participants did not feel obligated to keep a scheduled appointment in part because they felt disrespected when they were not scheduled for an appointment immediately after calling the clinic. The effect of this feeling was compounded by participants' lack of understanding of the scheduling system. Participants expressed the opinion that the clinic frequently overbooked and that the physicians and staff would actually be glad for the "free time" provided by their failure to keep their appointment.

These same perceptions may arise in scheduling appointments necessary to complete the referral process. That is, while parents may be very concerned over possible developmental delays, they may experience considerable anxiety over what they

might be told about their child's development or what the proposed interventions might entail. Also, if the appointment date is perceived as requiring a long wait, the parents' perception of the developmental concern might change and their sense of urgency diminish, resulting in a loss of interest in keeping the appointment.

Table 23. *Likelihood of IFSP Barrier Code Predicting Age at Referral*

Group A vs. B	Adjusted Odds Ratio	P - value	[95% Conf. Interval]	
Barrier Codes - (reference - Child/Family Issues)				
ES Capacity/Provider Issues	0.60	0.005	0.42	0.86
No Show/Unsuccessful Contact	1.31	0.099	0.95	1.79
Re - Referral	0.25	< 0.001	0.16	0.37

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.005, Removal P – value = 0.010)

Age at Exit. Age at exit was associated with age at referral. This is somewhat surprising since there is a cap on how old a child can be and still receive services through Early Steps. Also, there is a significant difference in the length of time children are served in the Early Steps Program between Groups A and B. Children in Group A have a median time in the program of 4.6 months while those in Group B are typically in the program for nearly a full year.

Reason for Exit. Reasons for exit are recorded as disposition codes in the Early Steps database. It is necessary to look closely at the formal definitions of these disposition codes to correctly interpret the analysis of the various reasons for exit.

Attempts to Contact Unsuccessful = All children under 3 with no IFSP and 3 consecutive unsuccessful attempts to locate the family or children with an IFSP who were inactive and reached the age of 3, or DEI only children with or without an IFSP.

Part B eligible, exiting Part C = All children determined to be eligible for Part B who exited (or will soon exit) Part C. This includes children who receive Part B services in conjunction with Head Start.

Not Eligible for ES Services = All children determined to NOT meet Part C/DEI Eligibility Criteria at initial evaluation or based on review of relevant collateral information.

Part B eligibility not determined = All children who reached their third birthday and their Part B eligibility has not been determined. This category includes children who were referred for Part B evaluation, but for whom the eligibility determination has not yet been made or reported.

In Table 24, the Reason for Exit "Not eligible for ES" was more than four times as likely to be used with infants who were older at the time of referral. These are typically infants for whom a less severe concern exists and the referral source (who may have been using a "wait and watch" approach) has decided to refer the child for Early Steps evaluation before the age limit of 3 years is reached.

Table 24. *Likelihood of Reason for Exit Predicting Age at Referral*

Group A vs. B	Adjusted* Odds Ratio	P – value**	[95% Conf. Interval]	
Reasons for Exit - (reference - Attempt to Contact Unsuccessful)				
Part B eligible, Exiting Part C	0.82	0.482	0.48	1.42
Not eligible for ES	4.24	< 0.001	1.94	9.29
Part B Eligibility not Determined	0.54	0.033	0.31	0.95
Other Reasons	0.50	0.016	0.29	0.88
Gestational Age – (reference – 37+ weeks)				
< 28 weeks	0.45	0.24	0.12	1.69
28 - 32	0.54	0.121	0.25	1.18
33 - 36	0.46	0.002	0.27	0.74

* Adjusted for referral source, referral reason, eligibility determination, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.005, Removal P – value = 0.01)

Non-Significant Variables

Several variables were associated with age at referral when analyzed in a single predictor model, but were not predictive of age at referral when other variables were added to the regression analysis. One of these variables was gender. Descriptive statistics provide a picture of gender differences in age at referral, for example, 70.3% of the infants in Group A (older at referral) were male. In the broader study population, the median age at referral for male infants was 19.6 months. This is an 8 month difference compared to the median age of female infants (11.6 months). However, including other variables in the analysis revealed that the odds of male and female infants being in Group A (those who were oldest at referral) were roughly equal. While the differences in gender composition of Groups A and B may be surprising to some, they do not contribute significantly to age at referral and therefore, no recommendations were generated based on gender.

Other variables that were not included in Model 2/Age at Referral were maternal education, race, county of birth and Medicaid status. These variables were not able to significantly predict age at referral and therefore, were not included in the most parsimonious model.

Multivariable Model 3/Age at Referral. In order to find a third and possibly fourth multivariable model, forward selection, based on Multivariable Model 1 (All Variables) was used to determine the best model to predict age at referral. This was done twice; first with an entry p – value of 0.005 (Multivariable Model 2) and again at 0.001 (Multivariable Model 3). Using an entry P – value of 0.005 produced the same model as Multivariate Model 2. Model 3 had more stringent entry criteria (P = 0.001 vs. P = 0.005 in Model 2) and so the third model excluded the variable

Eligibility Determination. Otherwise, it contained the same variables as Model 2.

The results of analyzing the data through Model 3 appear in Tables 25 and 26.

Table 25. *Likelihood of Referral Source and Referral Reason Predicting Age at Referral*

Group A vs. B	Adjusted *Odds Ratio	P – value**	[95% Conf. Interval]	
Referral Source - (reference - Physician)				
NICU	0.10	< 0.001	0.03	0.29
Community Agency/Provider	1.85	< 0.001	1.38	2.48
Self/Family	2.55	< 0.001	1.88	3.44
Other	2.45	< 0.001	1.84	3.26
Referral Reason - (reference DD Speech)				
DD At Risk	0.91	0.409	0.72	1.14
DD Behavior	0.64	0.159	0.34	1.19
DD Gross Motor	0.09	< 0.001	0.04	0.25
EC Genetic/Metabolic	0.31	0.004	0.14	0.70
EC Neurological	0.12	0.055	0.01	1.04
EC Hearing	0.03	0.001	0.00	0.25
Other	0.56	< 0.001	0.42	0.76

* Adjusted for referral source, referral reason, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.001)

Table 26. *Likelihood of Barrier Codes, Age at Exit, Reason for Exit and Gestational Age Predicting Age at Referral*

Group A vs. B	Adjusted* Odds Ratio	P – value**	[95% Conf. Interval]	
Barrier Codes - (reference - child/family issues)				
ES Capacity/Provider Issues	0.62	0.002	0.45	0.84
No Show/Unsuccessful Contact	1.49	0.002	1.16	1.91
Re - Referral	0.18	< 0.001	0.12	0.26
Age at Exit				
Each Additional Month	1.42	< 0.001	1.36	1.48
Reasons for Exit - (reference - attempt to contact unsuccessful)				
Part B eligible, Exiting Part C	0.34	< 0.001	0.23	0.49
Not eligible for ES	2.59	< 0.001	1.73	3.88
Part B eligibility not Determined	0.23	< 0.001	0.15	0.34
Other Reasons	0.48	< 0.001	0.34	0.69

Group A vs. B	Adjusted* Odds Ratio	P – value**	[95% Conf. Interval]	
Gestational Age (weeks) - (reference 37+ weeks)				
< 28 weeks	0.31	0.044	0.10	0.97
28 - 32	0.44	0.019	0.22	0.87
33 - 36	0.50	0.001	0.33	0.75

* Adjusted for referral source, referral reason, barrier codes, age at exit, reason for exit, gestational age. **(Entry P – value = 0.001)

Time to IFSP

The second phase of the statistical analysis addressed research question 2: What factors are associated with the length of time from referral to the Early Steps Program to the completion of the IFSP? All records in the dataset with a documented IFSP were assigned to one of two categories based on the time from referral to the development of an IFSP. Group C, comprised of those who had an IFSP completed within the state's requirement of 45 days from referral and Group D made up of those who waited longer than 45 days for an IFSP to be completed. Children who spent time in the NICU were excluded from this analysis because the initial developmental evaluation and IFSP were typically not completed until approximately 2 months adjusted age or post discharge. The rationale for this planned delay in developing the IFSP was so the child and family could settle in at home and allow adequate time to obtain a better indication of the child's development. The Early Steps Program has since changed that process and currently, NICU babies are referred to Early Steps at the time of discharge. However, because this planned delay was in effect during the study period, these infants were excluded to avoid the attribution of this delay to problems within the referral process.

The first step in investigating the impact of the predictor variables on time to IFSP was to apply the relevant tests of association. Children in Group C were found to be older at referral when compared to those in Group D (See Table 27). No other differences reached the pre-determined level of significance.

Table 27. *Results of Rank Sum test for Time to IFSP*

Variable		N	min	max	Median	IQR	p – value
Referral Age (months)	All	4,707	0	35.7	21.5	13.7	
	Group C	2,797	0.7	35.7	22.4	12.5	$p < 0.001$
	Group D	1,910	0	34.5	20.0	15.8	
Age at Exit (in months)	All	4,021	1.4	46.8	36.0	1.7	
	Group C	2,424	1.4	41.4	36.0	2.1	$p = 0.4361$
	Group D	1,597	2.7	46.8	36.0	1.1	
	Missing	686					
Gestational Age (in weeks)	All	4,707	20	45	40	2	
	Group C	2797	23	45	40	2	$p = 0.4313$
	Group D	1910	20	45	40	2	

Most of the categorical variables were associated with a longer wait for completion of the IFSP. The distribution of rates among referral sources apparently differed across levels of outcome 2. Approximately equal rates of referrals were attributed to Physicians and Community Agency/Providers for both groups C and D. While the rates of referral differed across Groups C and D for Self/Family referrals and Other Sources. Self/Family referrals were more likely to be in Group C than in Group D; while All Other Referral Sources were more likely to be in Group D. Reason for referral also displayed different rates for groups C and D.

Table 28. *Results of Chi – square tests by Time to IFSP*

Variable	Group C	Group D	Total
Referral Source ***			
Physician	28.0%	26.3%	27.3%
Self/Family	31.3%	22.3%	27.6%
Community Agency/Provider	21.4%	20.1%	20.9%
All Other Referral Sources	19.3%	31.4%	24.2%
N	2,797	1,910	4,707
Referral Reason***			
DD Speech	34.7%	27.8%	31.9%
DD At Risk	35.6%	41.2%	37.9%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	1.4%	1.9%	1.6%
DD Gross Motor	5.1%	5.2%	5.1%
EC Sensory Unspecified.	0.0%	0.0%	0.0%
EC Genetic/Metabolic	2.1%	2.7%	2.3%
EC Neurological	0.8%	1.0%	0.9%
EC Hearing	1.6%	2.6%	2.0%
Other	18.7%	17.6%	18.3%
N	2,797	1,910	4,707
Eligibility Determination***			
DD Speech	56.9%	51.7%	54.8%
DD At Risk	4.8%	7.2%	5.8%
DD Unspecified	0.0%	0.0%	0.0%
DD Behavior	1.1%	2.1%	1.5%
DD Gross Motor	8.0%	7.5%	7.8%
EC Sensory Unspecified.	0.0%	0.1%	0.0%
EC Genetic/Metabolic	2.2%	3.8%	2.8%
EC Neurological	1.5%	1.9%	1.7%
EC Hearing	1.9%	2.8%	2.3%
Other	18.0%	18.1%	18.0%
Missing	5.7%	4.8%	5.3%
N	2,797	1,910	4,707

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

Table 29. *Results of Chi – square tests by Time to IFSP*

Variable	Group C	Group D	Total
Barrier Codes			
Child/Family Issues	4.6%	41.7%	19.6%
ES Capacity/Provider Issues	1.6%	13.0%	6.2%
No Show/Unsuccessful Contact	2.5%	15.9%	7.9%
Re-referred	1.6%	14.8%	6.9%
Missing	89.8%	14.6%	59.3%
N	2,797	1,910	4,707
Reason for Exit			
Attempts to Contact Unsuccessful	3.8%	4.6%	4.1%
Part B eligible, Exiting C	36.7%	34.1%	35.7%
Not ES Eligible	1.1%	1.2%	1.1%
Part B not Determined	19.4%	20.7%	19.9%
Other	25.7%	23.0%	24.6%
Missing	13.3%	16.4%	14.6%
N	2,797	1,910	4,707
Gestational Age (weeks)*			
< 28	1.0%	1.2%	1.1%
28 - 32	3.2%	4.9%	3.9%
33 - 36	9.5%	9.1%	9.3%
37+	86.2%	84.8%	85.6%
N	2,797	1,910	4,707
Maternal Education***			
Grades 1 - 8	3.6%	5.2%	4.2%
Grades 9 - 12	4.0%	7.0%	5.2%
High School Graduate	14.8%	15.9%	15.2%
Partial College	11.7%	11.0%	11.4%
Bachelor's Degree	11.9%	6.4%	9.7%
Graduate	4.5%	3.7%	4.2%
Unknown	49.5%	50.8%	50.0%
N	2,797	1,910	4,707

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

There is no association between gender and Time to IFSP. Also, Medicaid status differed significantly for children in Groups C and D.

Table 30. *Results of Chi – square tests by Time to IFSP*

Variable		Group C	Group D	Total
Gender				
	Male	68.8%	66.4%	67.8%
	Female	31.2%	33.6%	32.2%
	N	2,797	1,910	4,707
Race ***				
	Black	10.8%	15.7%	12.8%
	White	49.7%	38.5%	45.2%
	Hispanic	24.1%	27.4%	25.5%
	Other	3.4%	3.6%	3.4%
	Unknown	11.9%	14.9%	13.1%
	N	2,797	1,910	4,707
County of Birth**				
	Hillsborough	73.2%	70.4%	72.0%
	Polk	23.9%	27.8%	25.5%
	Pasco	0.3%	0.3%	0.3%
	Manatee	1.2%	0.3%	0.8%
	Other	1.4%	1.2%	1.3%
	N	2,797	1,910	4,707
Medicaid Active***				
	NO	44.7%	29.1%	38.3%
	YES	55.3%	70.9%	61.7%
	N	2,797	1,910	4,707

Note: * - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$

Logistic regression models were built to calculate the odds ratio of being in Group C or D for each variable. These results are summarized in Tables 31 and 32. This analysis determined that for each increase in age at referral (in months), the odds of being in Group C increased by 3%. In terms of referral source, the analysis shows that infants referred by Physicians and those who were Self/Family-referred were equally likely to be in Group C (IFSP within 45 days). While infants referred by Community Agency/Providers were more likely to be in Group C; those referred

by Other Sources were less likely to be in Group C and therefore, more likely to wait more than 45 days for an IFSP.

When compared with children referred for DD Speech, those referred for DD At Risk, DD Behavior, EC Genetic/Metabolic or EC Hearing all had lower odds of receiving an IFSP within 45 days. When compared with children determined eligible for DD Speech, those eligibility codes for DD At Risk, DD Behavior, EC Genetic/Metabolic or EC Hearing each had lower odds of receiving IFSPs within 45 days. Children who had a gestational age of 28 – 32 weeks had decreased odds of receiving IFSPs within 45 days when compared to children who had a gestational age of 37 weeks or more.

Table 31. *Unadjusted Odds Ratios for Time to IFSP for Age at Referral, Referral Source and Referral Reason*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Age at referral	1.03	< 0.001	1.02	1.04
Referral Source - (reference - Physician)				
Community Agency/Provider	1.32	0.001	1.12	1.55
Self/Family	1.00	0.987	0.84	1.19
Other	0.58	< 0.001	0.49	0.68
Referral Reason - (reference DD Speech)				
DD At Risk	0.69	< 0.001	0.60	0.80
DD Behavior	0.59	0.028	0.37	0.94
DD Gross Motor	0.78	0.075	0.59	1.03
EC Genetic/Metabolic	0.62	0.017	0.42	0.92
EC Neurological	0.63	0.136	0.34	1.16
EC Hearing	0.50	0.001	0.33	0.76
Other	0.85	0.068	0.72	1.01
Eligibility Determination - (reference DD Speech)				
DD At Risk	0.60	< 0.001	0.47	0.77
DD Behavior	0.45	0.001	0.28	0.73
DD Gross Motor	0.97	0.755	0.77	1.21
EC Sensory Unspecified	0.62	0.736	0.04	9.93
EC Genetic/Metabolic	0.52	< 0.001	0.37	0.73
EC Neurological	0.70	0.126	0.45	1.10

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
EC Hearing	0.62	0.016	0.42	0.92
Other	0.90	0.214	0.77	1.06

As expected, there are no gender differences with respect to time to IFSP. Maternal education, however, did have an effect on this outcome. With increased maternal education children had increased odds of being in Group C (i.e., of getting an IFSP within 45 days). Also mothers whose educational status was unknown were more likely than mothers who reported completing Grades 1 – 8 to have children in group C.

Table 32. *Unadjusted Odds Ratios for Time to IFSP for Gestational Age, Maternal Education and Gender*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Gestational Age (weeks) - (reference 37+ weeks)				
< 28	1.03	0.802	0.84	1.25
28 - 32	0.64	0.003	0.48	0.86
33 - 36	0.85	0.553	0.49	1.47
Maternal Education - (reference - grades 1 - 8)				
Grades 9 - 12	0.84	0.347	0.58	1.21
High School Graduate	1.36	0.053	1.00	1.87
Partial College	1.56	0.007	1.13	2.17
Bachelor's Degree	2.70	< 0.001	1.91	3.81
Graduate	1.81	0.004	1.21	2.71
Unknown	1.43	0.016	1.07	1.91
Gender				
Females vs. Males	0.90	0.090	0.79	1.02

Racial differences were also evident as children from all other races had increased odds of receiving IFSPs within 45 days than did Black children. Birth county differences were seen for children from Polk and Manatee Counties. Children from Polk County had decreased odds of receiving an IFSP within 45 days when compared to children from Hillsborough County, while those from Manatee

County had increased odds of receiving an IFSP within 45 days when compared to children from Hillsborough County. Interestingly children with an active Medicaid status were half as likely as those with an inactive status to receive an IFSP within 45 days.

Table 33. *Unadjusted Odds Ratios for Time to IFSP for Race, County of Birth and Medicaid Status*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Race - (reference - Black)				
White	1.87	< 0.001	1.56	2.24
Hispanic	1.27	0.017	1.04	1.55
Other	1.36	0.083	0.96	1.94
Unknown	1.16	0.194	0.93	1.45
County - (reference - Hillsborough)				
Polk	0.83	0.005	0.72	0.94
Pasco	0.98	0.977	0.35	2.77
Manatee	3.61	0.004	1.51	8.64
Other	1.14	0.615	0.68	1.92
Medicaid Status				
Active vs. Inactive	0.51	< 0.001	0.45	0.58

Multivariable Model 1/Time to IFSP (All Variables). The model including all predictors, Model 1/Time to IFSP, is summarized in Tables 34 and 35. No variables were dropped from the model during the first backward stepwise regression process. When more strict entry and removal limits were set, referral reason, gestational age and county of birth differences disappeared. Variables that predicted time to IFSP were age at referral, referral source, eligibility determination, maternal education, race and Medicaid status. The results for age at referral indicated the older children were at referral the more likely they were to be in Group C (IFSP within 45 days).

Children referred by Other Sources had lower odds of receiving an IFSP within 45 days compared to those referred by Physicians.

Children determined to be eligible due to DD Behavior were less likely than children determined eligible due to DD Speech to be in Group C. While those determined eligible for DD Gross Motor were more likely to be in Group C than were those for DD Speech.

Table 34. *Adjusted Odds Ratios for Time to IFSP for Age at Referral, Referral Source, Referral Reason and Eligibility Determination*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Age at Referral	1.03	< 0.001	1.02	1.04
Referral Source - (reference - Physician)				
Community Agency/Provider	1.15	0.116	0.97	1.37
Self/Family	0.95	0.551	0.79	1.14
Other	0.63	< 0.001	0.53	0.75
Referral Reason - (reference DD Speech)				
DD At Risk	0.89	0.183	0.76	1.05
DD Behavior	0.85	0.564	0.49	1.47
DD Gross Motor	0.87	0.404	0.62	1.21
EC Genetic/Metabolic	1.31	0.328	0.77	2.23
EC Neurological	1.18	0.652	0.57	2.47
EC Hearing	0.78	0.505	0.38	1.61
Other	1.02	0.852	0.83	1.24
Eligibility Determination - (reference DD Speech)				
DD At Risk	0.83	0.189	0.63	1.10
DD Behavior	0.52	0.015	0.31	0.88
DD Gross Motor	1.45	0.008	1.10	1.91
EC Genetic/Metabolic	0.54	0.667	0.03	8.81
EC Neurological	0.74	0.207	0.46	1.18
EC Hearing	1.01	0.984	0.59	1.72
Other	1.16	0.675	0.59	2.27

Children whose mothers had a bachelor's degree were almost twice as likely as those with mothers who completed only Grades 1 – 8 to be in Group C. Racial

differences also persisted in that children who were White or Hispanic were more likely than Black children to be in Group C. Also, children whose Medicaid status was active were less likely than those whose status was inactive to be in Group C.

Table 35. *Adjusted Odds Ratios for Time to IFSP for Gestational Age, Maternal Education, Race, County of Birth and Medicaid Status*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Gestational Age (weeks) - (reference 37+ weeks)				
< 28	1.11	0.337	0.89	1.39
28 - 32	0.81	0.206	0.58	1.12
33 - 36	1.13	0.697	0.62	2.05
Maternal Education - (reference - Grades 1 - 8)				
Grades 9 - 12	0.86	0.459	0.58	1.28
High School Graduate	1.20	0.302	0.85	1.69
Partial College	1.28	0.175	0.90	1.84
Bachelor's Degree	1.76	0.004	1.19	2.60
Graduate	1.26	0.307	0.81	1.98
Unknown	1.29	0.119	0.94	1.79
Race - (reference - Black)				
White	1.45	< 0.001	1.19	1.78
Hispanic	1.34	0.007	1.08	1.66
Other	0.98	0.898	0.67	1.42
Unknown	0.99	0.915	0.77	1.27
County - (reference - Hillsborough)				
Polk	0.90	0.188	0.78	1.05
Pasco	0.50	0.227	0.16	1.54
Manatee	4.56	0.056	0.96	21.59
Other	1.38	0.379	0.67	2.82
Medicaid				
Active vs. Inactive	0.67	< 0.001	0.58	0.78

Multivariable Model 2/Time to IFSP. Using a backward stepwise regression selection procedure with an entry p – value of 0.10 and a removal p – value of 0.15, no variables were dropped from the model. Repeating the process with more strict criteria, entry p – value of 0.01 and removal p – value of 0.05 produced the model

with the predictor variables age at referral, referral source, reason for referral, maternal education, race and Medicaid status (Table 36). As with Model 1, the older children were at referral the more likely they were to have their IFSP completed within the 45-day timeframe. Children referred by Other Sources were less likely to receive an IFSP within 45 days than children referred by Physicians. When the eligibility determination code was DD Behavior, these children were less likely to be in Group C (IFSP within the 45-day limit) compared to children whose eligibility code was DD Speech. Again, just as in using Model 1/Time to IFSP, those with the eligibility code DD Gross Motor were more likely to have an IFSP within 45 days compared to those who were eligible based on DD Speech.

Table 36. *Adjusted Odds Ratios for Age at Referral, Referral Source and Eligibility Determination relative to Time to IFSP*

Group C vs. D	Odds	P - value	[95% Conf. Interval]	
Age at Referral	1.03	< 0.001	1.02	1.04
Referral Source - (reference - Physician)				
Community Agency/Provider	1.15	0.113	0.97	1.36
Self/Family	0.94	0.537	0.79	1.13
Other	0.63	< 0.001	0.53	0.75
Eligibility Determination - (reference DD Speech)				
DD At Risk	0.81	0.117	0.62	1.05
DD Behavior	0.51	0.007	0.31	0.83
DD Gross Motor	1.40	0.008	1.09	1.81
EC Genetic/Metabolic	0.52	0.645	0.03	8.38
EC Neurological	0.87	0.488	0.60	1.28
EC Hearing	1.08	0.743	0.67	1.74
Other	1.04	0.871	0.68	1.58
DD At Risk	1.13	0.148	0.96	1.34

Note: Entry p–value = 0.01, removal p- value 0.05

When the child's mother reported completing a bachelor's degree, the child was nearly twice as likely to have an IFSP within 45 days as those whose mother did not go beyond Grades 1 – 8 (Table 38). Racial differences were the same as in

Model 1/Time to IFSP in that White or Hispanic children were more likely to have an IFSP within the state-mandated timeframe compared to Black children. Also the same as Model 1/Time to IFSP, children whose family had an active Medicaid status were less likely than those whose status was inactive to receive an IFSP within the 45-day timeframe.

An explanation of the relationship between Medicaid status and Time to IFSP was sought by inquiring of the relevant Early Steps Program staff. The response indicated that delays in completing the IFSP are attributable to barrier issues (P. Grosz, personal communication, May 20, 2011). So, the connection between barrier codes and Medicaid status was explored. Table 37 shows the breakdown of barrier codes by Medicaid status. These data reveal that twice as many families who had an IFSP barrier code had a Medicaid status of active (30.7% vs. 15.4%). Therefore, it is likely that these barriers, rather than Medicaid status itself, contributed to the delays in completing the IFSP for these children. This leaves open the questions of how and why having an active Medicaid status is associated with increased barrier issues.

Table 37. *IFSP Barrier Codes by Medicaid Status: Active vs. Inactive*

Barrier Code	Active	Percent of Total	Inactive	Percent of Total
Child Issues	968	9.1%	638	6.0%
Natural Disaster	0	0.0%	1	0.0%
ES Capacity Issues	129	1.2%	70	0.7%
Family Issues	784	7.3%	365	3.4%
Insurance Approval Pending	2	0.0%	0	0.0%
No Show	283	2.6%	70	0.7%
Provider Issue	99	0.9%	70	0.7%
Re-referred	495	4.6%	180	1.7%
Unsuccessful Contact	518	4.8%	249	2.3%
Totals with Codes	3278	30.7%	1643	15.4%
No Code (Blank field)	3086	28.9%	2681	25.1%
Totals including blanks	6364	59.5%	4324	40.5%

Table 38. *Adjusted Odds Ratios for Maternal Education, Race and Medicaid Status relative to Time to IFSP*

Group C vs. D	Odds	P-value	[95% Conf. Interval]	
Maternal Education - (reference - Grades 1 - 8)				
Grades 9 - 12	0.86	0.467	0.58	1.28
High School Graduate	1.23	0.236	0.87	1.73
Partial College	1.31	0.143	0.91	1.87
Bachelor's Degree	1.82	0.002	1.24	2.67
Graduate	1.28	0.279	0.82	2.00
Unknown	1.30	0.103	0.95	1.80
Race - (reference - Black)				
White	1.45	< 0.001	1.19	1.78
Hispanic	1.35	0.006	1.09	1.67
Other	0.97	0.879	0.67	1.41
Unknown	1.01	0.924	0.79	1.30
Medicaid Status				
Active vs. Inactive	0.66	< 0.001	0.57	0.76

Note: Entry p–value = 0.01, removal p- value 0.05

Model Fitting and Checking

As each regression model was fit, various statistics were calculated to measure how well the predictor variable(s) actually predicted the outcome, in this case, Time to IFSP. Pearson's goodness of fit statistic was used to determine if each model was appropriate.

After fitting the single predictor logistic regression models for Time to IFSP the model fit was found to be unsatisfactory. This was determined to be due to inadequate model specification because once more complex models using multiple predictors from forward and backward selection were performed, the models displayed satisfactory fit. The lack of fit displayed by the single predictor models means that none of the variables alone can adequately explain Time to IFSP.

Backward stepwise regression was used to find the best models. For Age at Referral (the variable of interest relative to research question 1), the process was performed twice. Initially, the process was completed using an entry p–value of 0.1 and removal p–value of 0.15. The process was repeated a second time using an entry p–value of 0.005 and a removal p – value of 0.01. Next, forward stepwise regression was then used to find the best model for explaining age at referral, Multivariable Model 3/Age at Referral.

Table 39. *Model Comparisons for Age at Referral*

Comparison	Model	p – value
Model 1/Age at Referral vs. Model 2/Age at Referral	Model 1	0.5442
Model 2/Age at Referral vs. Model 3/Age at Referral	Model 2	< 0.001

Interestingly, the backward stepwise regression process for Time to IFSP using entry p–value 0.1 and removal p–value 0.15 produced the same model with all the predictors, Multivariable Model 1/Time to IFSP. The model found using entry p–value of 0.01 and removal p–value 0.05 was Multivariable Model 2/Time to IFSP. A likelihood ratio test of both models indicated that Model 1/Time to IFSP was not significantly better than Model 2/Time to IFSP. The results of this comparison are found in Table 40.

Table 40. *Model Comparison for Time to IFSP*

Comparison	Model	p-value
Model 1/Time to IFSP vs. Model 2/Time to IFSP	Model 1/Time to IFSP	< 0.2030

Summary

Initially, categories of selected variables were created to make the data analysis more meaningful in terms of the number of records in each category. This

was followed by the generation of descriptive statistics to obtain a clearer picture of the dataset. Utilizing Pearson's chi-square tests, the existence of an association between each variable and the two variables of interest was confirmed. Single predictor logistic regression models were built to calculate the unadjusted odds ratios for each variable of interest to quantify the associations found through the Chi-square tests.

Multivariable models were built to confirm whether any of the associations measured through the single predictor models would remain in the presence of other variables. Backward stepwise elimination, based on Multivariable Model 1 (All Variables) was used to determine the best model to predict Age at Referral. This was done with an entry p – value of 0.005 and removal p – value of 0.01(Multivariable Model 2). Then a forward selection process using an entry p – value of 0.001 produced the third model (Multivariable Model 3). The process was repeated for time to IFSP, this time using backward stepwise elimination. No variables were dropped from the model during the first backward stepwise regression process. When more strict entry and removal limits were set, several variables were dropped.

As each regression model was fit, the Pearson goodness of fit statistic was used to determine if each model was appropriate. After fitting the single predictor logistic regression models for Time to IFSP, it was found that the model fit was unsatisfactory. This was concluded to be due to inadequate model specification because once more complex models using multiple predictors from forward selection was performed, the models displayed satisfactory fit. The lack of fit displayed by the

single predictor models was interpreted to mean that none of the variables alone could adequately explain Time to IFSP.

Each variable that was found to have an association with either Age at Referral or Time to IFSP through the most parsimonious model was studied further in order to draw conclusions about the cause(s) of the association. These conclusions served as the basis for drafting initial recommendations for addressing those causes to reduce the delays in access to early intervention services to which they contributed.

Chapter 5 Key Findings and Recommendations

Summary of Purpose and Structure of Findings

Referral and demographic data on infants served by the Early Steps Program were analyzed to identify barriers to prompt access to early intervention services so that recommendations could be made for removing those barriers. Improving levels of prompt access to early intervention services should help infants and their families obtain better outcomes and reduce the costs associated with intervention services required later by identifying and addressing developmental concerns earlier.

Delays were identified at two junctures in the referral process; the time needed to identify a developmental delay or a condition that might lead to a developmental delay and actually make a referral (measured by Age at Referral) and the time infants and families waited for an Individual Family Services Plan following referral (measured by Time to IFSP). Variables from the dataset were analyzed to determine their association with these delays. Those that were shown to have a strong association with a delay were reviewed by the researcher and recommendations for actions that might reduce the delay were formulated. The subsequent sections of this chapter include a brief description of each key finding, a reference to where the supporting data are located in Chapter 4, the strength of the association between the variable representing each finding and the reference variable, a short discussion of the finding and one or more recommendations for how the delay could be addressed. Where no firm conclusions or recommendations could be made, topics were identified for future research.

Findings and Recommendations for Delays Identified by Age at Referral

Before a referral for developmental delay is made, someone must notice that the child's development in one or more areas is atypical. A parent may notice that the child is not on pace with other children of the same age or a physician may observe a delay or condition that has escaped the parent's notice. Some form of assessment, either through developmental impression or a formal checklist, takes place to confirm that the concern is worth pursuing. From this assessment, a referral may be made. This process differs somewhat from the referral process for established conditions, for example, spina bifida, which is diagnosed at birth. These conditions may be more readily observable, but require a physician's diagnosis to confirm. With developmental delays or established conditions, the parent must then exert a certain amount of effort toward follow through on the referral to ensure that it results in timely initiation of services. Thus the efficiency or timeliness of the referral process is impacted by the referral source, referral reasons and family efforts to comply with appointments and other follow-up actions. Delays were found relative to each of these three components.

Findings relative to referral source: Infants who were referred by parents or family members are almost three times as likely to be older at referral compared to infants referred by physicians (Table 21). This difference was highly significant ($p < 0.001$).

Bailey, Hebbeler, Scarborough, Spiker and Mallik (2004) interviewed a nationally-representative sample of 3,338 parents of young children who had been identified as having a disability or being at risk for disability. The children had recently been enrolled in a local early intervention program associated with Part C of the Individuals with Disabilities Education Act. Families of children who were older at the

time of referral reported a more difficult time accessing services than families of children who were younger at referral. When the child was older at referral, parents were less likely to have discussed their concerns with a healthcare professional and if they had shared their concerns with a physician or other healthcare provider, they were less likely to describe that person as helpful. These parents also responded that it took more effort for them to find out about early intervention services.

The Bailey et al. study cites perceptions that are likely to result when the parent does not seek a professional opinion of a developmental concern or the healthcare professional elects not to refer the child for further evaluation and the parents or family members are left to navigate the referral process on their own. Without guidance from someone who is familiar with the process, making a referral is likely to take longer and thus may contribute to the child being older at the time of referral (Hebbeler et al., 2007).

A nation-wide study of access to early intervention services found that parents were nearly unanimous in identifying the importance of greater public awareness of early intervention services, including clear descriptions of the services and resources available (Roberts, Akers & Behl, 1999). Responses collected through focus groups, individual interviews and a large-scale survey described the early intervention service system as a "complicated maze" (p. 11). These parents recommended development of user-friendly information and procedures for maneuvering through what they perceived as a confusing process. These perceptions support the conclusion that at least part of the explanation for infants referred by family members being older at referral is the difficulty faced by these individuals in working with the referral process.

Recommendations: Include information on developmental milestones in parent-friendly language in packets of material sent home by the birth hospital upon discharge of newborns. Ensure parents have contact information for the Early Steps Program and an explanation of how to make a self-referral. The materials should encourage parents to make and keep appointments for well-child visits and to ask their pediatrician about developmental screening with a standardized instrument.

Other Variables Associated with Age at Referral

Age at Exit and Reasons for Exit were also associated with being older at the time of referral. The Early Steps Program serves infants 0 to 3, so as children pass their third birthday, they are no longer eligible for Part C services. This puts a limit on their age at exit. Therefore, no recommendations were generated for at Age at Exit. One of the Reason for Exit codes (Not Eligible for ES) was more than 4 times as likely to be used with an infant who was older at referral than the reference code (Attempt to Contact Unsuccessful). Again, because this study is focused on improving access for infants who are eligible, no recommendations are needed to address this finding.

Findings and Recommendations for Delays Identified by Time to IFSP

In the sequence of events leading to the start of early intervention services, programs such as Early Steps exert the greatest amount of control over the time segment between a child's referral and IFSP development (Hebbeler et al., 2007). However, the timing of when things happen within this time span is not completely controlled by the program. A number of factors beyond the control of program staff can delay IFPS development. For example, parents may feel apprehension about whether or not to proceed due to fear of the unknown (Lacy, Paulman, Reuter & Lovejoy, 2004) or they

may procrastinate because dealing with their child's health problems requires so much of their time and energy (Hebbeler et al., 2007).

IDEA mandates that a meeting to develop the IFSP be held within 45 days of referral. In the National Early Intervention Longitudinal Study about 60% of the IFSPs were written within the mandated 45 day timeframe with some taking up to 100 days (Hebbeler et al., 2007). Hebbeler et al. provided no additional information about why the time between the referral and IFSP lasted more than 45 days for so many families other than the inability or reluctance of parents to follow through with IFSP-related actions.

In this present study, several factors were found to be associated with Time to IFSP. Age at referral, referral source, referral reason, maternal education, race and Medicaid status all proved to have some impact on whether or not the IFSP was completed within the mandated 45-day timeframe.

Finding Relative to the Impact of Age at Referral on Time to IFSP. The older children were at referral the more likely they were to receive an IFSP within the state-mandated 45-day timeframe (Table 34). This finding was also highly significant (OR = 1.03; P – value <0.001).

This finding is counterintuitive in the light of what is known about infants who were older at referral. For example, the present study found that being older at the time of referral was associated with barrier codes Child/Family Issues and No Show/Unsuccessful Contact, referral reasons DD At Risk and DD Speech and being referred by a parent or family member. The presence of two of these three factors, barrier codes and family referral, would seem to make it less likely that an IFSP would be completed in a timely manner for these infants.

No studies could be located that examined the relationship of age at referral and time to complete the IFSP. Therefore, no firm conclusions can be drawn relative to this finding. Future research should consider the impact of the relevant referral reasons (DD At Risk and DD Speech) as possible factors in making it more likely that an IFSP is completed within the 45-day timeframe for children who are older at referral. Likewise, developmental delays in speech are typically noted when the child is older, but are so common as to make the development of the IFSP a more routine effort. Therefore, infants with this referral reason may be older at referral, but the IFSP may be completed in a shorter period of time than what is required for infants who are referred because of behavioral concerns.

Finding Relative to the Impact of Referral Source on Time to IFSP. Children referred from Other Sources had lower odds of receiving IFSPs within 45 days than did those referred from Physicians (Table 34). This finding was highly significant ($P < 0.001$; $OR = 0.63$.)

No research was found that provided corroborating or contradictory findings concerning the influence of referral source on the timely completion of the IFSP. Early Steps Program staff indicated that delays in completing the IFSP are due to barrier issues (P. Grosz, personal communication, May 20, 2011). Descriptive analysis of the dataset shows that infants referred by Other Sources (those other than physicians, NICU, community agencies/providers and family members) were slightly more likely to have barrier issues (41.8% compared to 37.7% for those referred by physicians). Therefore, barrier issues may be at work in this situation, causing more of the infants referred by Other Sources to wait longer for an IFSP.

It may also be significant that the category of Other Sources was made up of referral sources that made far fewer referrals during the study period than physicians, the NICU, self/family or community agencies and providers. While no research was identified that cited differences in the time required to complete an IFSP associated with the frequency with which a referral source made referrals, this topic is worth considering for future research. Future research should also examine the relationship of referral source to timely completion of the IFSP in a broader context to confirm whether or not referral source contributes to delays in completing the IFSP.

Findings Relative to the Impact of Eligibility Determination on Time to IFSP. Two findings arose from the data on eligibility codes and the time that elapsed from referral to the development of an IFSP. Children with an eligibility code of DD Behavior were less likely than children with an eligibility code of DD Speech to receive an IFSP within the state-mandated 45-day timeframe (Table 34). The adjusted odds ratio was 0.52 and the P – value was 0.015. Secondly, Children with an eligibility code of DD Gross Motor were more likely than children with an eligibility code of DD Speech to receive an IFSP within the state-mandated 45-day timeframe (Table 34; OR = 1.45, P – value = 0.008).

The reference variable for this comparison was DD Speech. Therefore, children coded as eligible through DD Behavior were much more likely to have a wait time for IFSP that exceeded 45 days than those who with an eligibility determination of DD Speech. Neither of these findings was significant at the level chosen for these comparisons, but they are close and therefore, worth further scrutiny.

Research on the influence of eligibility determination on the timely development of an IFSP is sparse. However, findings on how referral reason impacts the intensity or urgency of referral may shed light on why children with behavioral concerns (DD Behavior) waited longer for an IFSP. For example, Sices, Feudtner, McLaughlin, Drotar & Williams (2004) conducted a survey-based study to describe physician referral practices for children with developmental delays and to test whether the probability of referral is increased in specific situations. They found that cases when the child presented avoidant behaviors were associated with a more intense pattern of referral to early intervention services compared with cases where the parent's concern focused on disruptive behaviors. The study authors had incorrectly hypothesized that physicians would be more likely to refer a child with disruptive behaviors because this type of behavior in children has been associated with higher levels of parenting stress. Sices et al. concluded that the participating physicians may have recognized a potential autism spectrum disorder in the child with avoidant behaviors, whereas the child with disruptive behaviors might have been considered less likely to require early intervention services. Their findings may reveal a tendency to interpret disruptive behavior as a less urgent reason for referral. If this is true, then children displaying disruptive behavior may be perceived by the referral source and parent or family members as having a lower priority need for services and therefore may be allowed to wait longer for a completed IFSP.

In a profile of referrals for developmental delay, Shevell, Majnemer, Rosenbaum, & Abrahamowicz (2001) noted that parents expressed concern for motor delay earlier than for other developmental issues, concluding that it likely reflects the documented parental awareness of and sensitivity to the achievement of early motor milestones.

Because parents are more aware of these milestones and can observe gross motor delays more readily, they may be more persistent in pursuing early intervention services and thus more likely to keep appointments and complete tasks associated with the development of an IFSP. This, in turn, can result in more timely completion of the IFSP.

Recommendations: Ensure that Early Steps Program staff members are aware that families in which the infant is referred for behavioral concerns may be under greater stress and may have an increased likelihood of failing to keep appointments and complete IFSP-related tasks. Therefore, additional support and/or reminders may be necessary to see that the family fulfills the requirements for completing the IFSP in a timely manner.

Finding Relative to Maternal Education. Children whose mother had a bachelor's degree were almost twice as likely as those with mothers who completed only Grades 1 – 8 to receive an IFSP within the 45-day state-mandated timeframe (Table 35; OR = 1.82, P – value = 0.002).

When Bailey et al. (2004) studied responses from families of different levels of education they found that in nearly all the comparisons they made, there were differences in experiences and perceptions of services based on education level of the primary caregiver, with families with less-educated caregivers generally having a more negative experience. For example, 12% of families in which the primary caregiver had less than a high school education reported that it took a lot of effort to find out about early intervention services, compared with 9% of those with a bachelor's degree or higher. This difference was consistent with findings related to household income with 13% of those making less than $15,000 annually reporting that it took a lot of effort, compared with only 7% of those with annual household incomes between $50,000 and $75,000.

Bailey et al. stated that "demographic differences in how families experienced the process of beginning early intervention were especially strong with regard to awareness of the IFSP, wanting more involvement in the decision-making process, perceiving services as highly individualized, and whether early intervention professionals ignored the caregiver's opinion" (p. 893).

The above comment is consistent with findings reported by Hebbeler et al. (2007) that 31% of the families in which the mother did not complete high school were unaware that a formal plan of services had been completed even though the interviews took place within 4 months of the development of the IFSP. This percentage is significantly higher than the 18% of the total sample of families who were not aware that an IFSP had been developed.

The finding concerning Maternal Education should be considered in light of the fact that while all categories of Maternal Education that included a high school diploma (HS graduate, partial college, bachelor's degree and graduate level work) were associated (although not significantly) with receiving an IFSP within 45 days, so was the education level code of Unknown. One possible explanation is that mothers with at least a high school education are better equipped to navigate the process of obtaining early intervention services and the Unknown category probably includes a fair representation of mothers who graduated from high school. (This is not a required field on the Early Steps Demographic Form and therefore, there were an extensive number of records with Maternal Education as Unknown.)

Recommendations: Early Steps staff should note maternal education as an indicator of the parent's ability to work within the constraints and challenges of the process for

enrolling their infants in early intervention services. Those parents who have an education level below high school graduate should be provided with additional support and follow-up to ensure that their infants receive services in as timely a manner as those of mothers with higher levels of education.

Finding relative to Race. White and Hispanic children were more likely than Black children to receive an IFSP within the 45-day state-mandated timeframe (Table 35). The odds ratio for White children was 1.45 (P – value <0.001) and for Hispanic children, 1.35 (P – value = 0.006).

Through an extensive review of the literature, Rose et al. (2010) found that among families with children who had special health needs, parental perception of those needs was associated with racial differences in the level of access and use of mental health care resources. For example, Black caregivers were less likely than White caregivers to report mental health and behavior problems in their children even when greater levels of stress were reported by Black caregivers (Jaffe, Liu, Canty-Mitchell, Qi, & Swigonski, 2005). Also, Black parents were significantly less likely than White parents to perceive that their children needed mental health care or specialty health care services (Mayer, Slifkin, & Skinner, 2005; Porterfield & McBride, 2007). Both of these factors, less perception of need and reluctance to report health concerns, can contribute to greater delays in complying with follow-up actions that should take place during the time between referral and the development of an IFSP.

Recommendations: Take steps to make Early Steps Program staff members aware of possible racial differences in perception of need and willingness to share health-related concerns so that they respond appropriately when working with Black families to ensure

they feel comfortable with the IFSP process. This should include training for relevant Early Steps Program staff in cultural competency so they understand cultural differences in how families perceive and act toward programs such as Early Steps and can interact with these families in an appropriate and effective manner.

Finding relative to Medicaid Status. Children whose Medicaid status was active were less likely to receive an IFSP within the state-mandated 45-day timeframe than those whose status was inactive (Table 35; OR = 0.66, P – value <0.001).

As explained earlier, delays in completing the IFSP are attributable to barrier issues (P. Grosz, personal communication, May 20, 2011). An exploration of the connection between barrier codes and Medicaid status revealed that twice as many families who had an IFSP barrier code had a Medicaid status of active (30.7% vs. 15.4%). Because of the likelihood that it is barrier issues, rather than Medicaid status, that contributed to the delays in completing the IFSP for these children, the recommendation focuses on closer examination of the most common barrier codes.

Recommendations: Review current plans to address barrier issues with Early Steps Program staff and focus problem-solving efforts on priority barriers such as Child/Family Issues, No Show/Unsuccessful Contact and infants who are re-referred. Training in cultural competency, mentioned in the previous recommendation, may also be helpful for Early Steps staff in dealing with families who present the barrier issues that were found to impact Time to IFSP.

Limitations

The findings and recommendations of this study are limited by several aspects of the data that provided the basis for the study. First, as is the case with all retrospective

studies, there is little opportunity to fill in missing data. Infants whose records made up the dataset and their families have moved on with their lives, many of them leaving the area and therefore, no follow-up to collect or clarify information was possible. In addition, several fields on the Early Steps Demographic Form are not required fields. For example, none of the fields in the section on program participation are marked as required on the form. Even some of the required fields were not completed on every record. For example, maternal education is identified on the Early Steps Demographic Form as a required field, but of the 10,688 records in the dataset, 6,124 (57.3%) were coded as "unknown."

Other aspects of the data that were problematic include the validity of parent self-reporting. Gestational age was calculated based on parent interviews and therefore, may be subject to some level of error.

Changes in Early Steps Program procedures, that is, how the referral process works, also introduce limitations on the conclusions and recommendations. The best example is the change in timing of referral and IFSP development for NICU infants. During the study period, it was Early Steps policy to wait until the infant had been at home for some time before a referral was made and the IFSP completed. This was intended to allow the infant and family to have an adjustment period and to obtain a clearer picture of the infant's development. Since the close of the study period, this practice has changed. At present, referral for early intervention services are made at the time of discharge and the IFSP is completed within the 45-day window.

In addition, significant changes have been made in eligibility criteria. (Please see the section entitled *How are infants referred to Early Steps?* in the first chapter of this

study.) The impact of these changes on the referral process is not known. Therefore, some recommendations of this study may not be necessary under the newly established eligibility criteria. A review of the conclusion and recommendations with Early Steps staff is planned and should include discussion of which, if any, recommendations may no longer apply.

Implications for Future Research

Often our research findings lead to more questions that warrant further investigation. The findings from this analysis are quite interesting, but nonetheless, must be understood in the context of the limitations of the dataset and the limitations of the researcher to obtain more comprehensive information. It is important to note that the Early Steps referral process has not been evaluated on a formal level in the past and that this is the first time that this dataset was requested by a researcher outside of the Florida Department of Health system.

The Early Steps referral process is complex and requires a fundamental understanding of the premise of the Early Steps program, current funding sources and challenges, and the local healthcare delivery models or standards of care. Recommendations for valuable changes to this referral process are difficult to make using quantitative data alone. Adding a qualitative component to the study design would allow for a deeper understanding of the true issues that are encountered on a daily basis by stakeholders and end users of the program. Qualitative research is most useful when there is a need to better understand what the true issues are. Engaging stakeholders to look objectively at the Early Steps referral process and identify where changes might produce better outcomes is imperative. This could be accomplished through several

avenues: an online survey tool to assess how stakeholders understand and utilize referrals to Early Steps when there is a concern about a child's development and through focus group sessions or in-depth interviews with key stakeholders (i.e., parents of children enrolled in the program, Early Steps administrative staff, local NICU discharge coordinators). Secondly, because secondary data were used and much of the intake information was parent-reported, a linkage to more accurate demographics could further strengthen the quality of the data and reduce the amount of missing or inaccurate data. In particular for this study, linking to birth certificate data would have improved the correlations between what was reported as gestational age on the Early Steps intake form, as an example, to what was recorded at birth in the hospital. Thirdly, this data analysis was specific to one geographical area in Florida, Hillsborough and surrounding counties. This area of Florida may not be absolutely representative of the general population and therefore, broadening the sample to include catchment areas in other parts of the state might uncover other findings. And lastly, as stated in the previous section, recent reductions in funding have altered eligibility criteria for Early Steps participation, therefore, recommendations provided in this research project may not be plausible today. In the future, an assessment of the Early Steps referral process as it is currently implemented would be suggested.

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Appendices

Appendix A: Terms and Definitions

Adaptive Delay A measure of the child's ability to problem solve through intuition, perception, and verbal and nonverbal reasoning. Moreover, it encompasses the ability not only to learn and understand but also to retain this information and apply it as needed. Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Assistive Technology Device Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities. Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Battelle Developmental Inventory-2 A "standardized, individually administered assessment battery of key developmental skills in children from birth through 7 years of age" (Battelle Development Inventory – Examiner's Manual, p. 1). It involves observations of the child, parent and/or caregiver interviews, and interactions with the child using toys, games and tasks. During sessions with the child, the examiner(s) observes the child's ability to follow directions, interact, and perform selected tasks. The child's performance is scored based on standardized criteria using a simple three point scoring system.
Source: TATS *e*Updates. Retrieved January 13, 2011 at http://www.tats.ucf.edu/docs/eUpdates/Evaluation-8.pdf

Brain maturity or **cerebral maturation** The developmental changes occurring in the brain of premature infants. They are assessed on four parameters—myelination, cortical folding, glial cell migration, and germinal matrix distribution—to determine a composite measure called the total maturation score (TMS).
Source: Childs, Ramenghi, Cornette, Tanner, Arthur, Martinez, & Levene (2001).

Cerebral palsy A group of disorders of the development of movement and posture,

causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder

Source: Bax, M., Goldstein, M., Leviton, A., Paneth, N., Dan, B. & Jacobsson, B. (2005).

Developmental Evaluation and Intervention (DEI) Program A program to identify and track infants at high risk for developmental disabilities. The program provides services to eligible infants who are admitted to hospital Neonatal Intensive Care Units. Infants must meet both medical and financial eligibility criteria and must be determined to need DEI services.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Developmental screening The process of systematically identifying children with suspected developmental delay who need further assessment. Screening refers to the process of proactively testing whole populations of children to identify those at high risk of clinically significant but, as yet, unsuspected deviations or delay from normality.

Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Developmental surveillance An ongoing process of monitoring the status of a child by gathering information about the child's development and behavior from multiple sources, including skillful direct observation of the child's behavior and elicitation of concerns from parents and relevant professionals

Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Early intervention The process of providing services, education and support to young children who are deemed to have an established condition, those who are evaluated and deemed to have a diagnosed physical or mental condition (with a high probability of resulting in a developmental delay), an existing delay or a child who is *at-risk of

developing a delay or special need that may affect their development or impede their education. The purpose of early intervention is to lessen the effects of the disability or delay. Services are designed to identify and meet a child's needs in five developmental areas, including: physical development, cognitive development, communication, social or emotional development, and adaptive development.

Source: Wright, P. W. & Wright, P. D. (2010). Wrightslaw Homepage. Retrieved on December 18, 2010 at http://www.wrightslaw.com/info/ei.index.htm

Early intervention services **S**ervices to infants and toddlers from birth to three years of age who have developmental delays or disabilities, and their families. Typical services include physical, speech, and occupational therapy. By assisting children in their early, formative years, these early intervention services seek to enhance infants' and toddlers' development, reduce costs by decreasing the need for special education, minimize the likelihood of institutionalization, and increase families' abilities to meet their children's needs.

Source: Office of Program Policy and Governmental Accountability (2006)

Early Steps A comprehensive, multidisciplinary, community-based, family-focused system that provides a coordinated system of early intervention services for infants and toddlers with a developmental delay or an established condition which may result in a delay. This umbrella program has three components: the Developmental, Evaluation and Intervention (DEI) Program, the IDEA, Part C Program, and services provided under Chapter 393, Florida Statutes, for children, birth to 36 months.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Extremely preterm Applied to infants born prior to 27 weeks, weighing less than 1,000 grams.

Source: Adams, Alexander, Kirby and Wingate (2009).

Fine and Gross Motor Delay Motor development encompasses both gross motor ability (the control of large groups of muscle involved in walking, sitting, or transferring from one position to another) and fine motor abilities (the manipulation of objects with the hands in order to eat, draw, play etc). Children progress through motor milestones in an orderly fashion, attaining these functions in a clear and sequential process. Motor delay is defined as a significant delay in motor abilities without a delay in other developmental categories.

Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Fine motor skills The coordination of small muscle movements which occur e.g., in the fingers, usually in coordination with the eyes.

Source: Wikipedia; Accessed October 8, 2009 http://en.wikipedia.org/wiki/Fine_motor_skill

Florida Diagnostic and Learning Resources System (FDLRS) A student support system responsible for the location and identification of children who may be eligible for IDEA services (Child Find). FDLRS also provides public awareness, screening, in-service training, technology and parent services as a support for school districts, families and community organizations that serve children with disabilities, birth through twenty-one years of age.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT) A council that advises the Early Steps State Office in the implement of a statewide system - coordinated, comprehensive, multidisciplinary interagency programs providing early intervention services to infants and toddlers with disabilities and developmental delays. FICCIT consists of members who are appointed by the Governor and represent the population of the state.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-

Kids/home/resources/es_policy_0710/Definitions.html

Full term or term Gestation of greater than or equal to 37 weeks
Source: Vanderveen, Bassler, Robertson & Kirpala (2009).

Individualized Family Support Plan (IFSP) Process A family-centered planning process involving the family, evaluators, the service coordinator, service providers and others, which results in a written plan of early intervention services to meet the identified outcomes for an individual child and family.
Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Individualized Family Support Plan (IFSP) Team A group consisting of the family, the service coordinator, and at least two (2) professionals from two different disciplines who have been or are currently involved in the assessment or provision of services to the child. The team has specialists available, as appropriate, to address the individualized needs of infants and toddlers served. The IFSP Team works with the family to assess the functional status of the child, the priorities, concerns and resources of the child and family, develop the initial Individualized Family Support Plan, assist in the implementation and review of progress toward achievement of identified outcomes, makes modifications to the IFSP when appropriate, and assists in developing transition plans when appropriate.
Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Individuals with Disabilities Education Act (IDEA), Part B A federal program that requires states to provide free appropriate public education in the least restrictive environment to students with disabilities from age three through twenty-one. Eligibility criteria are mandated through federal and state regulations, and services are supported with public funds. Also see Pre-kindergarten Program for Children with Disabilities.
Source: Early Steps Program Definitions Retrieved January 2, 2011 at

http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Individuals with Disabilities Education Act (IDEA), Part C A federal program that states participate in voluntarily, that requires states to provide a statewide, community based, comprehensive, coordinated, family-focused, multidisciplinary, interagency program of early intervention services for infants and toddlers, birth to age three, with established conditions or developmental delays and their families.
Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Interim Individualized Family Support Plan A plan used in unique situations to serve as the vehicle for authorizing the initiation of early intervention services prior to the completion of evaluations, determination of eligibility and the development of the initial Individualized Family Support Plan.
Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Language Delay This area consists of articulation, receptive and expressive language skills, and the use of nonverbal symbols. They encompass a major stream of development, arising from the interaction between innate communication abilities and environmental influences. Any significant delay in language or speech skills without a delay in other developmental domains is categorized as a developmental language disorder, developmental dysphasia, or specific language impairment.
Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Low birth weight Applied to infants born weighing less than the birth weight expectancy of full-term infants, i.e., less than 3,000 grams.
Source: Morse et al., (2009) and Oken et al., (2003).

Moderately-Preterm Gestation between 33 to 36with a birth weight between 1,500 to 2,499

Source: Adams, Alexander, Kirby and Wingate (2009).

Natural Environments The day-to-day routines, activities and places that promote learning opportunities for an individual child and family. This means settings, including home and community settings that are natural or normal for the child's age peers who have no disabilities.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Near-term Applied to infants born at 33 to 36 weeks with a birth weight of 1,500 to 2,499. Near-term has been replaced by "late-preterm" in most studies and articles.

Source: Raju, Higgins, Stark, & Leveno (2006).

Neurodevelopmental outcomes Categories of neurodevelopmental outcomes include cognitive, neuromotor, vision, hearing and behavior. Deficits or delays may exist across any or all of these categories of outcomes. Examples include cerebral palsy, low IQ, hearing loss, and other medical conditions.

Source: Fawke, J. (2007). *Seminars in Fetal & Neonatal Medicine. 12*, 374e382

Personal or Social Delay These areas encompass the child's interactions, as shown by the formation and maintenance of relationships and responsiveness to the presence of others. Psychosocial or social delay presents itself over time as behavioral abnormalities that differ from normal behavioral responses by their quantity, severity, nature, and duration. Personal development involves the formation of self-help skills in various activities of daily living, such as feeding, dressing, and toileting.

Source: Rydz, D., Shevell, M., Majnemer, A., and Oskoui, M. (2005). Developmental Screening. Retrieved on December 10, 2010 at http://www.medscape.com/viewarticle/504722

Primary Service Provider (PSP) The identified professional on the IFSP team that works with the child/family/primary caregivers on a regular basis and with other members of the team providing services directly, through consultation and/or joint visits.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at

http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Referral The procedures or steps taken by an individual (e.g., physician) or entity (e.g., NICU) on behalf of an infant, a toddler or a preschooler to obtain the opinion, supports, or services of another individual (e.g., early childhood special education practitioner) or entity (e.g., early intervention program).

Source: Tracelines. (2004) v1 (1) Retrieved November 1, 2010 at http://www.tracecenter.info/tracelines/tracelines_vol1_no1.pdf

Referral Source An individual, facility or agency that refers a child to the appropriate public agency within the system. Referral sources include: hospitals, (including prenatal and postnatal facilities), physicians, parents, day care programs, local educational agencies, public health facilities, other social service agencies, and other health care providers.

Source: Early Steps Program Definitions Retrieved January 2, 2011 at http://www.doh.state.fl.us/AlternateSites/CMS-Kids/home/resources/es_policy_0710/Definitions.html

Sensitivity The ability of a test to correctly identify those who have a condition or disease or The proportion of children with a condition (developmental delay) who are correctly identified as having the condition by the test.

Source: Sices, L. (2007). Developmental Screening In Primary Care: The Effectiveness Of Current Practice And Recommendations For Improvement. Commonwealth Fund. Retrieved December 16, 2010 at http://www.commonwealthfund.org/usr_doc/1082_Sices_developmental_screening_primary_care.pdf?section=4039

Specificity The ability of a test to correctly identify those who do not have a condition or disease or The proportion of children without a condition (developmental delay) who are correctly called negative by the test.

Source: Sices, L. (2007). Developmental Screening In Primary Care: The Effectiveness Of Current Practice And Recommendations For Improvement. Commonwealth Fund. Retrieved December 16, 2010 at http://www.commonwealthfund.org/usr_doc/1082_Sices_developmental_screening_prim

ary_care.pdf?section=4039

Standard deviation In probability theory and statistics, the standard deviation of a statistical population, a data set, or a probability distribution is the square root of its variance. A low standard deviation indicates that the data points tend to be very close to the mean, whereas high standard deviation indicates that the data are spread out over a large range of values.
Source: Wikipedia; Accessed October 8, 2009;
http://en.wikipedia.org/wiki/Standard_deviation

Very low birth weight Applied to infants born weighing less than the birth weight expectancy of moderately-preterm infants, i.e., less than 1,500 grams but greater than the birth weight expectancy of extremely preterm infants, i.e., greater than 1,000 grams.
Source: Morse et al., (2009) and Oken et al., (2003).

Appendix B: List of Acronyms

ASQ	Ages and Stages Questionnaires
BDI-2	Battelle Developmental Inventory-2
CMS	Children's Medical Services
ELBW	Extremely low birth weight
FICCIT	Florida Interagency Coordinating Council for Infants and Toddlers
IDEA	Individuals with Disabilities Education Act
LBW	Low birth weigh
LES	Local Early Steps Office
NICU	Neonatal Intensive Care Unit
OPPAGA	Office of Program Policy Analysis and Government Accountability
SQL	Structured Query Language
UF-MCHERDC	University of Florida Maternal Child Health and Education Research and Data Center
VLBW	Very low birth weight