

**DEVELOPMENTAL
COMPREHENSIVE SCREENING
PROJECT**

**Does the implementation of a
validated developmental
screening tool make a difference?**

**by
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**Center for Applied
Demography &
Survey Research
University of Delaware**

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prepared for

**American Academy of Pediatrics - Delaware Chapter
and
Advances in Management, Inc.**

by

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SUMMARY

In March 2009, the Delaware Chapter of the American Academy of Pediatrics (DE-AAP) received a grant from the *Blueprints for the Community Fund* of Blue Cross Blue Shield of Delaware. The DE-AAP contracted with Advances in Management, Inc. to administer a pilot project with support from the Division of Public Health to expand the work of the Assuring Better Child Health and Development (ABCD) Project in Delaware to address the developmental needs of young children, birth to age three, within pediatric practices. The overall goal of the project was to ensure that all children have comprehensive screening consistent with the policies of the American Academy of Pediatrics- occurring at 9, 18, and 30 months.

The Center for Applied Demography & Survey Research (CADSR), University of Delaware, conducted the project evaluation to determine if more children were identified with possible developmental or behavioral delays with the use of a validated developmental screening tool than without the use of such a tool. This report will analyze the identification of concerns for developmental delays prior to and after the implementation of the validated developmental screening tool and any referrals that resulted.

This report is divided into four sections. The first section provides a literature review that will give the reader insight into the role of early intervention programs and developmental screening tools as well as research that highlights some of the benefits of both. The second section includes the methods section. This section details the process that was used to evaluate the developmental screening program, the selection criteria for the patient population as well as the pre implementation (control group) and post implementation (screening group) evaluation process. The third section presents the results of the evaluation project. The results section includes an overall demographic review of both the control group and the screening group, comparisons between both groups and a detailed analysis of the screening group. A discussion of the results and findings concludes the report.

INTRODUCTION

Developmental screening has garnered much interest in increasing the early identification of youth who have developmental or behavioral delays. Research has shown that approximately 17 percent of children in the United States have a developmental or behavioral disability.¹ According to current literature, detection of developmental disorders is lower than their actual prevalence.² Early childhood developmental delays are a strong indicator of possible later developmental disabilities including mental retardation, cerebral palsy, speech disorders, autism and learning disabilities later in childhood.³ Fewer than 30 percent of children with developmental and behavioral disorders are identified before school entrance. One of the major benefits of identifying developmental delays early is that intervention may improve or correct the delays.

Early intervention is defined as a process of assessment and therapy provided to children from birth to age three to facilitate normal cognitive and emotional development and prevent developmental disability or delay. Early intervention programs consistently improve outcomes for children when compared to children who did not have the benefit of participating in such programs. Some of the benefits that early intervention programs have demonstrated include improved school performance, a lower rate of criminality, and within families a reduction in child abuse and neglect notifications, among others.⁴ For children who might have needed special education services in the classroom, early intervention programs help reduce that need prior to their entering school. Children who receive early intervention services are less likely to be held back in school when compared to children who need but do not receive early intervention services.

Research has demonstrated that intervention programs are cost-effective and have lifelong benefits, and that developmental attainment is maximized when intervention begins earlier in a child's life.⁵ Current research has led the American Academy of Pediatrics (AAP) to

¹ CDC Developmental Screening Fact Sheet

http://www.cdc.gov/ncbddd/actearly/pdf/parents_pdfs/DevelopmentalScreening.pdf

² Council on Children with Disabilities, Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. American Academy of Pediatrics Policy Statement, Pediatrics, Volume 118, Number 1, July 2006

³ Sices et al. How Do Primary Care Physicians Manage Children with Possible Developmental Delays? A National Survey with an Experimental Design. Pediatrics Vol. 113 No. 2 February 2004

⁴ Fish, Ellen, Stronger Families Learning Exchange "The Benefits of Early Intervention," Stronger Families Learning Exchange Bulletin No. 2 Spring/Summer 2002 pp. 8-11

⁵ Rydz, et al. Screening for Developmental Delay in the Setting of a Community Pediatric Clinic: A Prospective Assessment of Parent-Report Questionnaires. Pediatrics Volume 118, Number 4, October 2006.

advocate for the identification of developmentally delayed children prior to age two.⁶ The AAP currently recommends that developmental screening tests be administered regularly at the 9 month, 18 month and 30 month well-child visits.

The purpose of early identification of children at risk for developmental or behavioral delays through the use of a validated screening tool is to identify children needing additional clinical evaluations, and if indicated, involve them in early intervention programs. According to the AAP, “developmental screening is the administration of a brief standardized tool aiding the identification of children at risk of a developmental disorder.” Using validated screening tools more accurately identifies these children when compared to simply asking general questions about a child’s behavior or development.

Formalized screening tools are a way for physicians to have a standardized measure in place to allow them to accurately screen children for the types of delays that potentially need additional testing rather than relying on clinical judgment. Studies have shown that “pediatricians’ use of their clinical judgment tended to under-identify developmental impairments.”

An additional finding of concern in recent literature is that when a child is identified as having a risk for a delay they are not always referred for further evaluation or early intervention services. Caregivers surveyed in a study reported that there was a “relatively short period of time between first concerns and first diagnosis (mean difference: 1.5 months). However, the mean time difference between caregiver report of diagnosis and agency report of referral for early intervention was more than five months.”⁷ One of the major findings identified in current literature is once a physician identifies a child as having a risk or concern for developmental or behavioral delay, a large proportion of the children are not referred to early intervention services.

Early intervention services are provided under Part C of IDEA (Individuals with Disabilities Education Improvement Act of 2004 and reauthorization in 2007) to children from birth to three years of age who have been identified as having a developmental or social/emotional delay. The purpose of this program is to provide early identification of children who have developmental or behavioral delays or those who are at risk for delays and to enroll them in supports and services that help to address their needs before they enter primary school.

The conditions that qualify for early intervention eligibility under Part C of the IDEA in Delaware fall under two categories. The first includes established medical conditions including,

⁶ Ibid.

⁷ Bailey, Donald et al, First Experiences with Early Intervention: A National Perspective, Pediatrics Vol. 113 No 4, April 2004.

for example, a variety of chromosomal and genetic disorders as well as other conditions ranging from low birth weight to severe infectious diseases, which place a child at high risk for developmental delay. The second category that qualifies children for Part C eligibility and early intervention is based on developmental delays in any one or more of five skill areas. These areas are communication, cognitive skills, fine and gross motor physical skills, adaptive and independent living skills, and social/emotional skills. The State of Delaware has an Interagency Coordinating Council that has defined these guidelines for eligibility. The Delaware Department of Health and Social Services uses a multidisciplinary team assessment to evaluate delays when compared to age-expected levels of development. Infants and toddlers are determined eligible for early intervention based on results from these evaluations, clinical observations, and other medical information.

A validated screening tool allows the provider to make an objective decision with clear markers to identify concerns for developmental or behavioral delays in each patient who visits the practice for a well-child visit at 9, 18 and 24-30 months. Without the use of a validated screening tool the identification of concern for developmental delay is subjective. The use of a validated screening tool provides the primary care provider with clear objectives that allow for identification of these concerns for developmental or behavioral delays in specific areas that indicate a need for further evaluation or monitoring.

The validated screening tool used in this developmental screening project is the Parents' Evaluation of Developmental Skills (PEDS). PEDS is designed for children between six months and eight years of age. This tool is used to screen for developmental and behavioral problems needing further evaluation.⁸ PEDS is considered an evidence-based surveillance screening tool.

A previous study found that providers screened more children for developmental and behavioral delays with the usage of the PEDS screening tool than without the use of the tool.⁹ In this same study, when compared to the same-aged children before screening and after screening, more children were identified with behavioral concerns in the two-year-old age group and more children with developmental concerns were identified in the three-year-old age group.¹⁰ Due to the ease of use of the PEDS tool, the previous study identified it as particularly useful in an urban primary care setting.

⁸ Ibid.

⁹ Schonwald, et al. Routine Developmental Screening Implemented in Urban Primary Care Settings: More Evidence of Feasibility and Effectiveness. *Pediatrics* Volume 123, Number 2, February 2009

¹⁰ Ibid.

The PEDS validated screening tool is answered by parents and can be completed in less than five minutes in the clinical setting.¹¹ With regards to sensitivity (identification of children with disabilities) and specificity (identification of children without disabilities), PEDS sensitivity is 74% to 80% and specificity is 70% to 80%. To add to the ease of use for parents, the PEDS tool is available in both English and Spanish and can be translated into multiple languages. The tool is also written at a fifth grade level.

¹¹ Ibid.

METHODS

The goal of this evaluation was to analyze the implementation of a developmental screening pilot program and to determine if more children were screened and referred for early intervention services before the implementation of a developmental/behavioral screening tool or after the implementation of this tool. This pilot program implemented the Parents' Evaluation of Developmental Status (PEDS), a validated developmental screening tool, at four pediatric practices in the three counties (New Castle, Kent and Sussex) in Delaware.

The targets of the pilot program were children who attended well-child visits at 9 months (8-11 months), 18 months (17-20 months), 24 months (23-26 months) and 36 months (34-37 months) of age. The Center for Applied Demography & Survey Research, University of Delaware (CADSR) performed a quantitative evaluation to measure the ratio of pediatric patients that received a validated developmental screening, identification of delays and any resulting referrals before and after the implementation of the PEDS tool at all four sites.

During the pilot program, a control group was first evaluated. This control group was evaluated for the six months (March 15, 2009 to September 13, 2009) prior to the implementation of the PEDS screening tool. During the project implementation period, the screening group consisted of children from age groups matched to the control groups. The screening group included all of the children who attended well-child visits within the designated age range after the use of PEDS began. The project implementation period lasted for six months, from September 14, 2009 to March 12, 2010 (see Appendix C).

Patient Population

The patient population for both the control and screening groups consisted of children who were regular patients of the physician practice. Patients who were only seen at the hospital immediately after birth, those who were not considered a regular patient of the physician, or patients who were no shows to their appointment were excluded from the evaluation. Patients who were identified as already being in the screening group were excluded from analysis in the control group. Additional exclusion criteria included individuals who were previously diagnosed with a behavioral or developmental delay and/or were already enrolled in early intervention services. Missing data was also excluded from analysis. The age groups used for evaluative purposes for both the control group and the screening group included children in the following age ranges: 9 months (8-11 months), 18 months (17-20 months), 24 months (23-26 months) and 36 months (34-37 months) of age.

Pre Implementation

Each of the practice sites was evaluated separately as a case study due to the differing demographic make-up of each physician practice. The selected practice sites each provided a data set with no identifiable details for all of the children who were seen for 9 month, 18 month, 24 month and 36 month well-child appointments within the six months prior to the project implementation period (March 15, 2009 to September 13, 2009). For the sampling process, a past patient list, which included the newly generated identification number, gender and date of birth, was provided from each site.

Advances in Management, Inc. (AIM), the primary contractor overseeing the project, ensured that the PEDS tool was implemented in each practice. They were also responsible for making sure that each practice site could be identified with a unique identifier number. AIM assigned each patient on the patient list a unique identifier number from which the control group was drawn. The unique identifier number was a different number than the child's social security number, date of birth, and the HIPAA identifier number. The unique identifier numbers that identified patients who were in the group from which the control group was to be drawn were then provided to CADSR. CADSR selected a random sample of approximately 125 unique identifiers from the list of children who attended their well-child appointments at each of the practices for an overall total of 500 charts to be reviewed. During the selection process of the control group, additional samples had to be drawn to comply with our pre determined selection criteria (see Appendix B). Due to the differing set-ups of each practice, additional detail on how each practice structured their data collection method of patients in the six months prior to the implementation to the PEDS tool is listed in Appendix B.

After the random samples were chosen, three nurse educators employed by AIM and assigned to one of the four sites, were provided with the unique identifier numbers randomly selected to comprise the control group. With assistance from staff at each practice, the nurse educators then pulled the patient charts for review and completion of the pre implementation data collection tool. CADSR provided to the nurse a data collection tool (identified with the identification number) that was filled in for each selected patient with details on the demographics of the patient and data identified as being related to developmental screening (see Appendix D). Data was collected on the control group from March 15, 2009 to September 13, 2009, which was the time period immediately preceding the implementation of the PEDS tool.

Post-Implementation

The post-implementation evaluation included the number of referrals that were made for behavioral or developmental delays after the introduction of the PEDS tool and what types of delays were identified. Each of the three nurse educators assigned to one of the four practice sites was responsible for having the post-implementation data collection survey filled out for every patient who was present at their physician's office well-child visit at 9 months (8-11 months), 18 months (17-20 months), 24 months (23-26 months) or 36 months (34-37 months) (see Appendix C). The patients who attended their well-child appointments after the implementation of the PEDS tool (September 14, 2009) consisted of the screening group. A unique identifier number determined by the nurse educators was assigned to each of the data collection tools and clearly identified the specific practice from which the data collection tools were completed. The post-implementation data collection tool was identical to the pre-implementation data collection tool with the exception of one additional section that listed questions that were specific to the PEDS tool (see Appendix E). The data collection tools were collected monthly by AIM and provided to CADSR. The post-implementation data collection tools were evaluated, and the results of the data were analyzed to compare the pre-implementation data to the post-implementation data. The post-implementation data collection period lasted from September 14, 2009 to March 12, 2010.

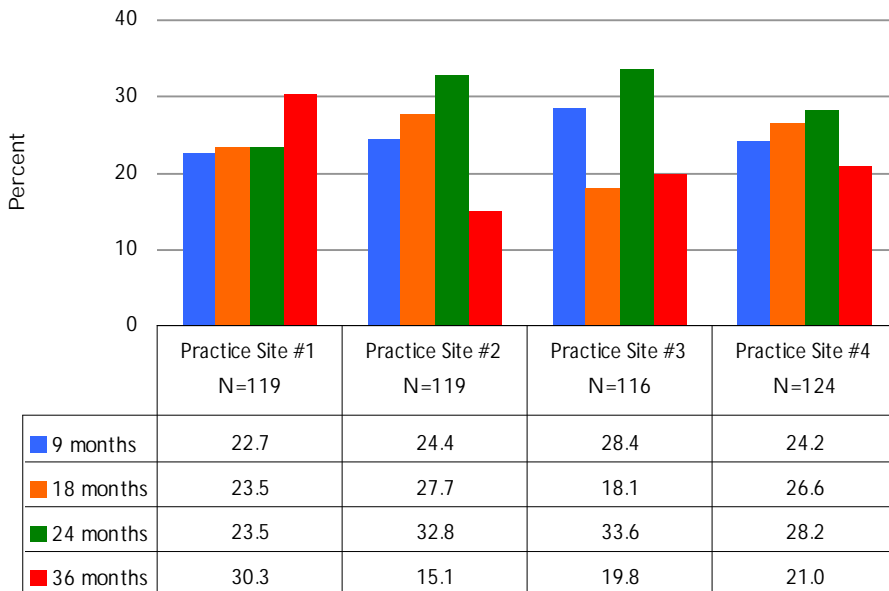
RESULTS

Demographics

Figure 1.1 and 1.2 provides a summary of the control and screening groups who were both evaluated using 9, 18, 24 and 36 month well-child visits.

Figure 1.1

Pre-Implementation – Month of Well-child Visit for Control Group

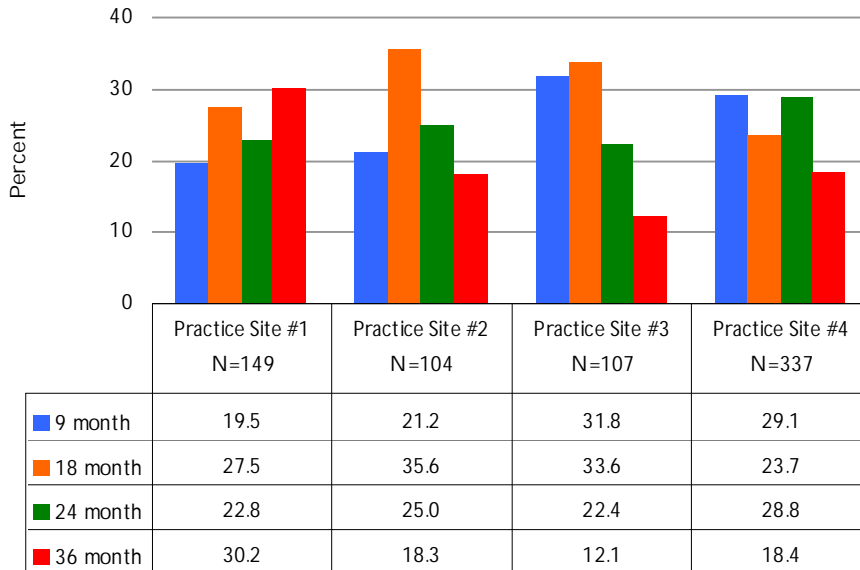


Source: Center for Applied Demography & Survey Research
University of Delaware

When analyzing the data, the number of patients from each group was roughly evenly divided with between 18 and 34 percent of the patients in the control group among each of the four well-child visit categories.

Figure 1.2

Post-Implementation – Month of Well-child Visit for Screening Group

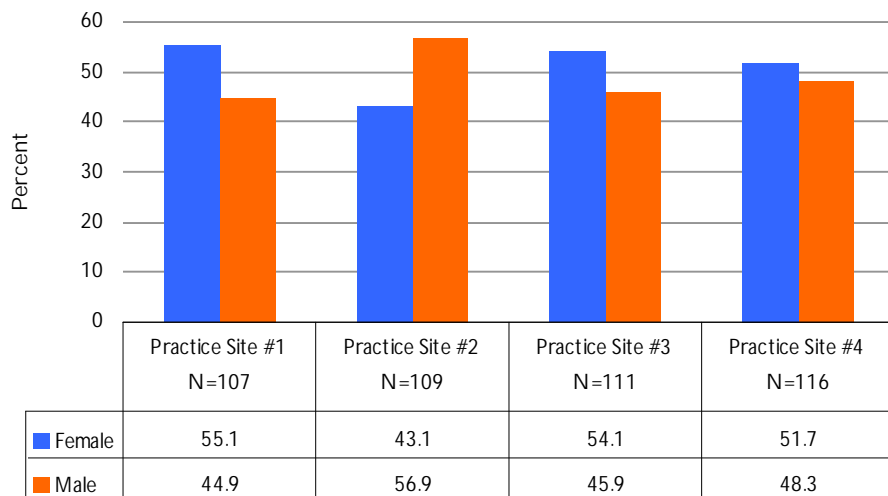


Source: Center for Applied Demography & Survey Research
University of Delaware

With regards to the screening group, the ages at well-child visits were for the most part equal with the exception of **Practice Site #3**. In **Practice Site #3** only about 12 percent of the patients in the screening group were 36 months at the time of the screening.

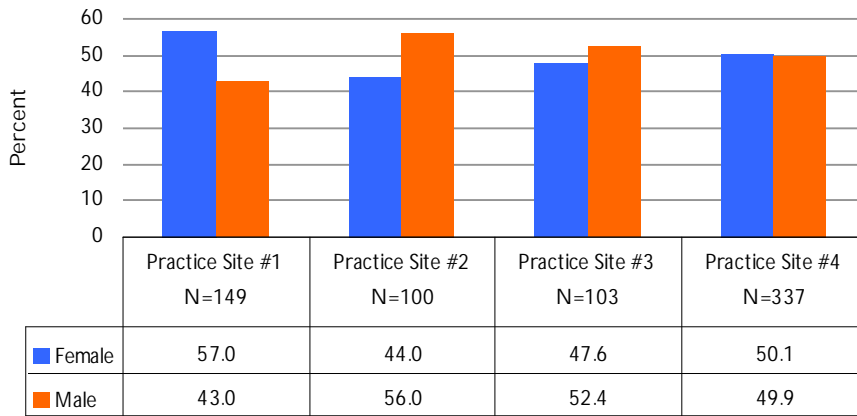
Figure 1.3

Pre-Implementation Control Group - Gender



Source: Center for Applied Demography & Survey Research
University of Delaware

Figure 1.4
Post-Implementation Screening Group - Gender

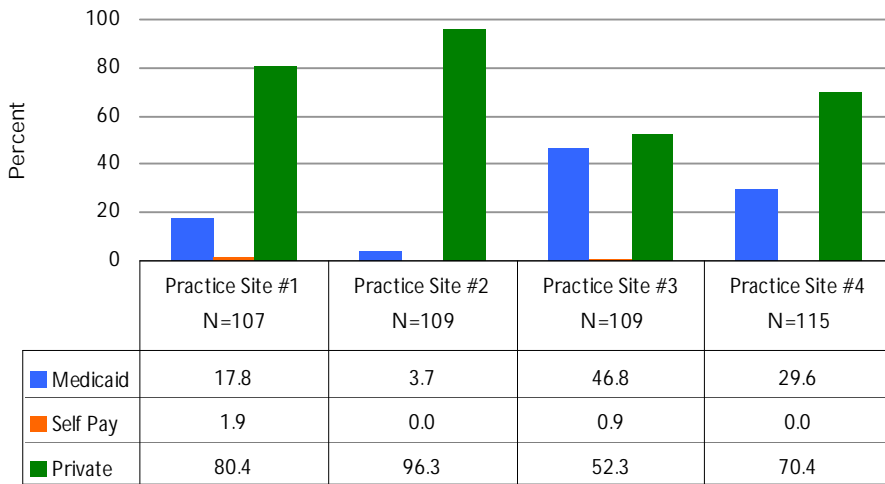


Source: Center for Applied Demography & Survey Research
University of Delaware

Gender was relatively evenly divided among the four practice sites for both the control and screening groups. Above Figures 1.3 and 1.4 identifies the gender divisions for each of the four practice sites for both the control and the screening group. For the control group, a slightly higher percent of **Practice Sites #1, #3 and #4** were primarily made up of females while the majority of patients at **Practice Site #2** were males. Among the screening groups, a slightly higher percent of the patients in **Practice Sites #2 and #3** were male.

Figure 1.5 and 1.6 identifies the proportion of patients who were covered by either Medicaid, Self Pay or Private insurance.

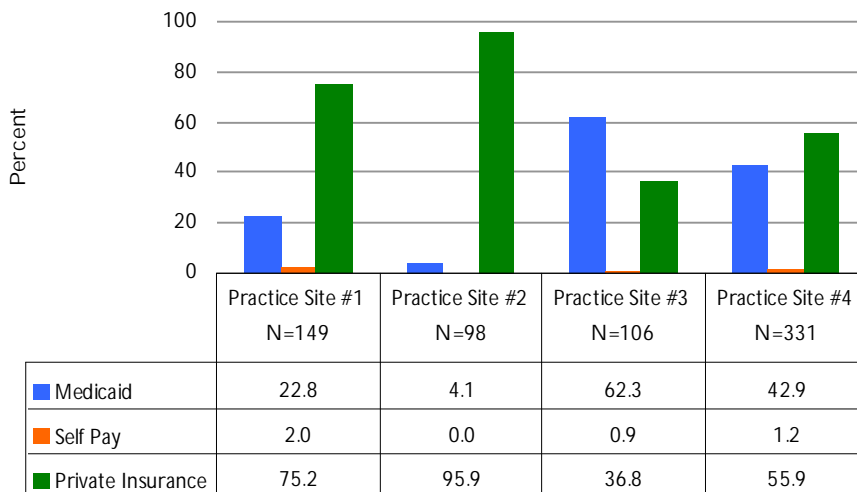
Figure 1.5
Pre-Implementation Control Group– Type of Insurance



Source: Center for Applied Demography & Survey Research
University of Delaware

The majority of patients in the control group including **Practice Sites #1, #2 and #4** utilized private insurance. **Practice Site #3** was the one exception, with about half of the patients utilizing Medicaid while the other half utilized private insurance (Figure 1.5).

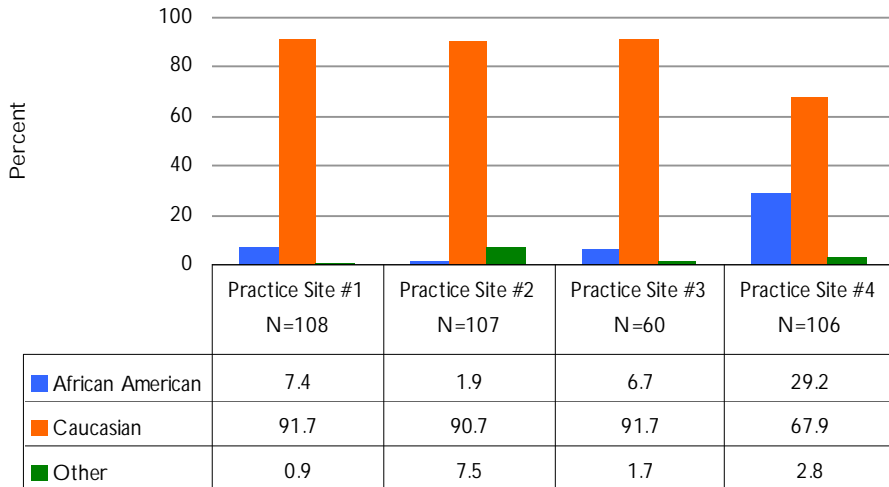
Figure 1.6
Post-Implementation Screening Group – Type of Insurance



Source: Center for Applied Demography & Survey Research
University of Delaware

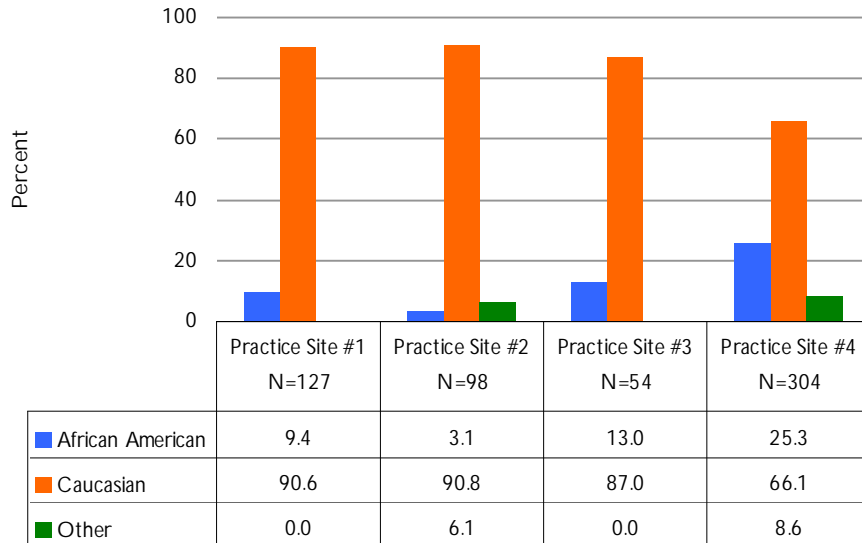
The type of insurance utilized by the patients within each practice site in the screening group varied. While the majority of the patients in **Practice Site #1 and #2** utilized private insurance, roughly 43% of patients in **Practice Site #4** and about 62% of **Practice Site #3** were insured by Medicaid (Figure 1.6).

Figure 1.7
Pre-Implementation Control Group – Race of Patient



Source: Center for Applied Demography & Survey Research
 University of Delaware

Figure 1.8
Post-Implementation Screening Group– Race of Patient

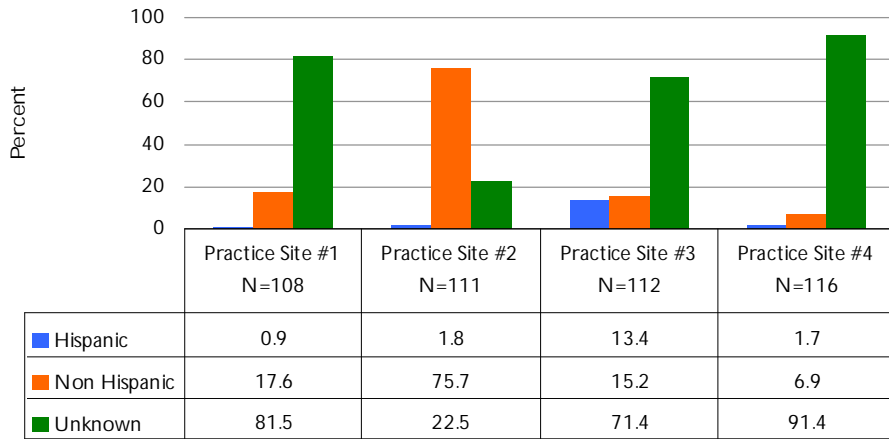


Source: Center for Applied Demography & Survey Research
 University of Delaware

In both the control and screening groups, the majority of the patients at each practice site were Caucasian, however, almost one third of the **Practice Site #4** patient population was identified as African American in both groups (Figures 1.7 and 1.8).

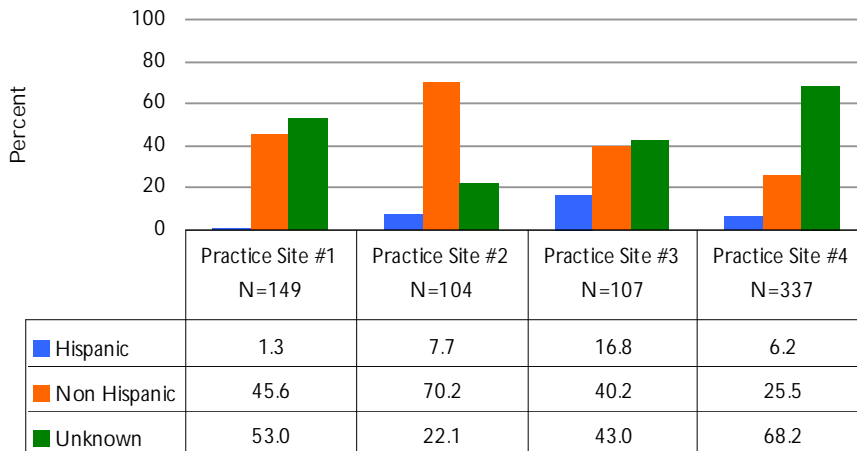
Figure 1.9 and 1.10 identifies the patient population by ethnicity. It is important to note that data was missing for approximately two-thirds of the patients in the control group in response to ethnicity and the screening group did not include data on about half of the patients in the sample.

Figure 1.9
Pre-Implementation Control Group – Ethnicity of Patients



Source: Center for Applied Demography & Survey Research
University of Delaware

Figure 1.10
Post-Implementation Screening Group – Ethnicity of Patients



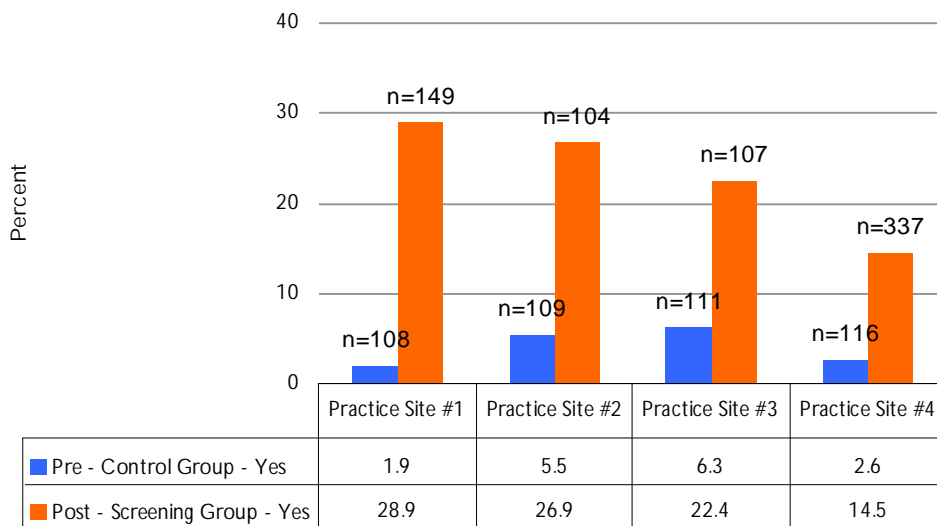
Source: Center for Applied Demography & Survey Research
University of Delaware

The majority of patients from all four practice sites were Non Hispanic although **Practice Site #3** had a higher proportion of Hispanic patients than **Practice Sites #1, #2 and #4**. In **Practice Site #3** approximately 13.4% of the control group was identified as Hispanic while about 16.8% of the patients in the screening group were identified as Hispanic (Figures 1.9 and 1.10).

Comparisons

Figure 2.1 demonstrates that among the control groups that were evaluated in the six months prior to the implementation of the PEDS tool, the percent of patients identified as being at risk for behavioral or developmental delays ranged from two to six percent for all four practice sites. These proportions are in stark contrast to the proportion of patients who were identified as possibly having a behavioral or developmental delay after the implementation of the PEDS tool.

Figure 2.1
Developmental or Behavioral Delay Identified

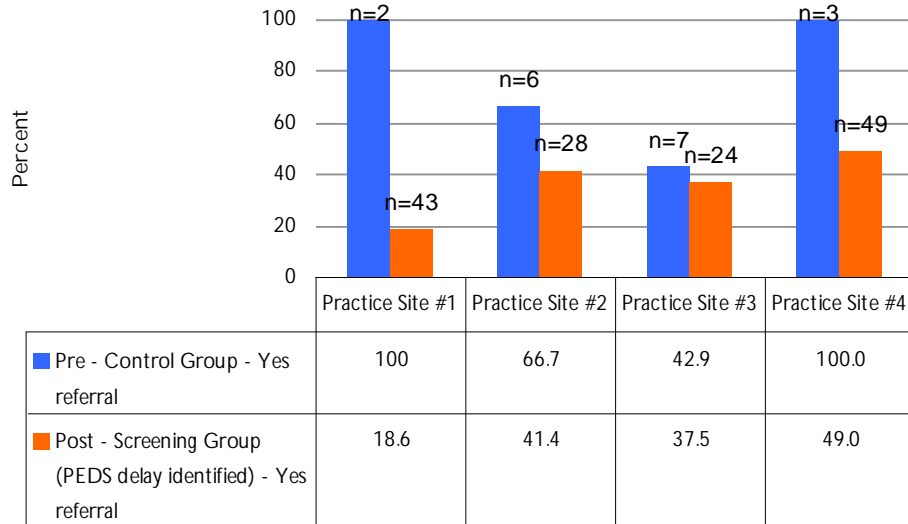


Source: Center for Applied Demography & Survey Research
University of Delaware

After the PEDS tool was implemented, all four of the practices identified a much larger proportion of patients who possibly had developmental or behavioral delays, with further evaluation recommended. Patients from the screening group identified as possibly having a developmental or behavioral delay ranged from a low of about 15% within **Practice Site #4** to a high of 29% in **Practice Site #1**.

Figure 2.2

Formal Referral Made for Patients Identified With a Possible Developmental or Behavioral Delay

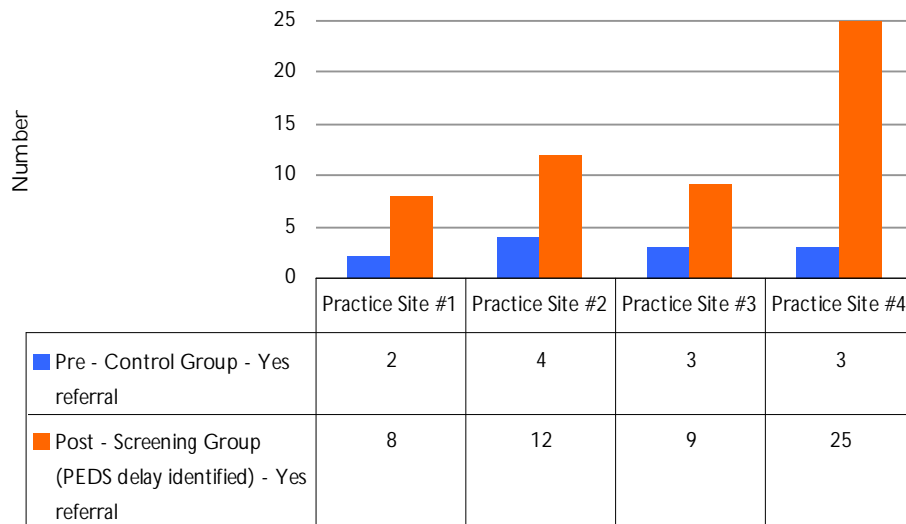


Source: Center for Applied Demography & Survey Research
University of Delaware

The control and screening group data were analyzed and highlighted in Figures 2.2 and 2.3 to determine what percent of patients identified as possibly having a developmental or behavioral delay were referred for further treatment and/or evaluation.

Figure 2.3

Number of Formal Referrals Made for a Developmental or Behavioral Delay



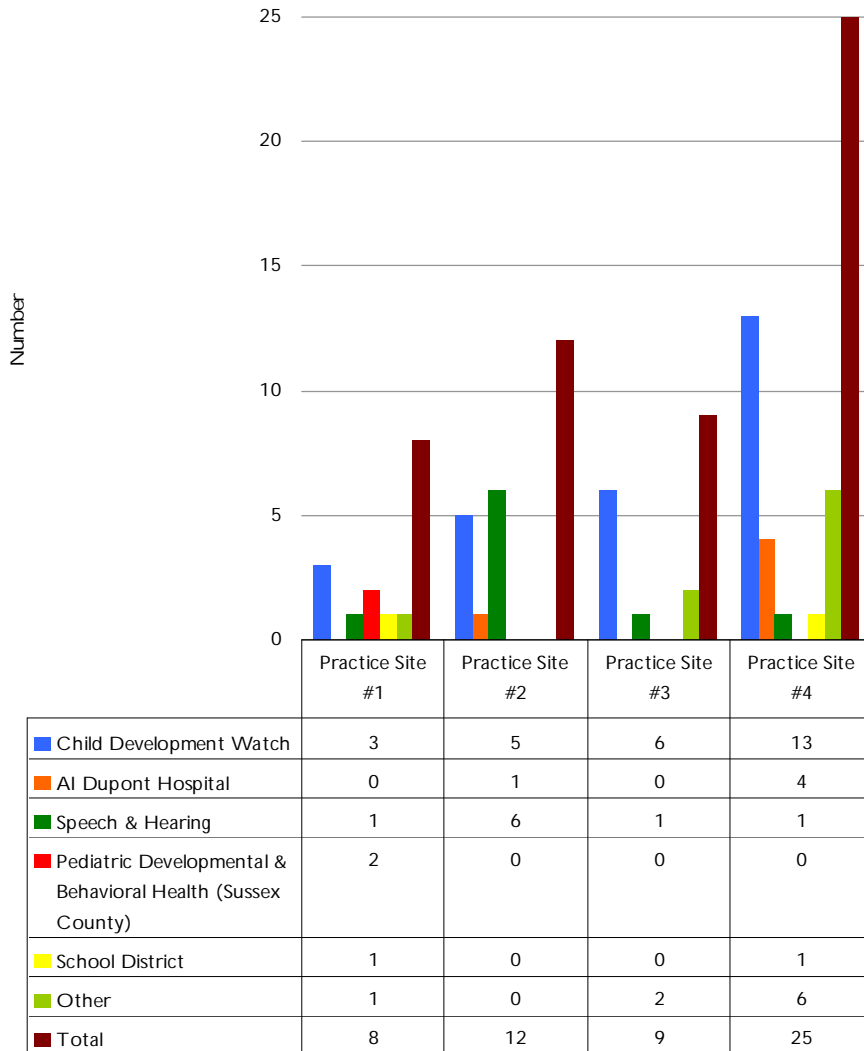
Source: Center for Applied Demography & Survey Research
University of Delaware

Of the control group, all of the patients at **Practice Sites #1** and **#4** who were identified as being at risk for a behavioral or developmental delay were referred for additional evaluation and/or treatment. About 67% (4) of patients at **Practice Site #2** and 43% (3) of patients at **Practice Site #3** from the control group were referred for additional evaluation or treatment. Of the control group, the majority of children who were identified as possibly having a developmental or behavioral delay and referred were sent to Child Development Watch for further assessment early intervention services (Figures 2.4).

While a much higher proportion of patients were identified as possibly having a behavioral or developmental delay after the implementation of the PEDS tool, a significantly smaller proportion of the patients were referred for additional treatment and/or evaluation. It is interesting to note that while the proportion of children formally referred for additional evaluation was higher among the control group, the actual number of children referred for additional evaluation was higher in the screening group (Figure 2.2 and 2.3). From the screening group, 19% (8) of the patients in **Practice Site #1** identified as possibly having a behavioral or developmental delay were also referred for additional evaluation. **Practice Sites #2** and **#3** both referred roughly 40% (12 and 9 respectively) of their patients for additional treatment and/or evaluation while **Practice Site #4** had the highest proportion and number of patients who were referred for additional treatment and/or evaluation at 49% (25).

Figure 2.4

Location of Formal Referral made for a Developmental or Behavioral Delay



Source: Center for Applied Demography & Survey Research
University of Delaware

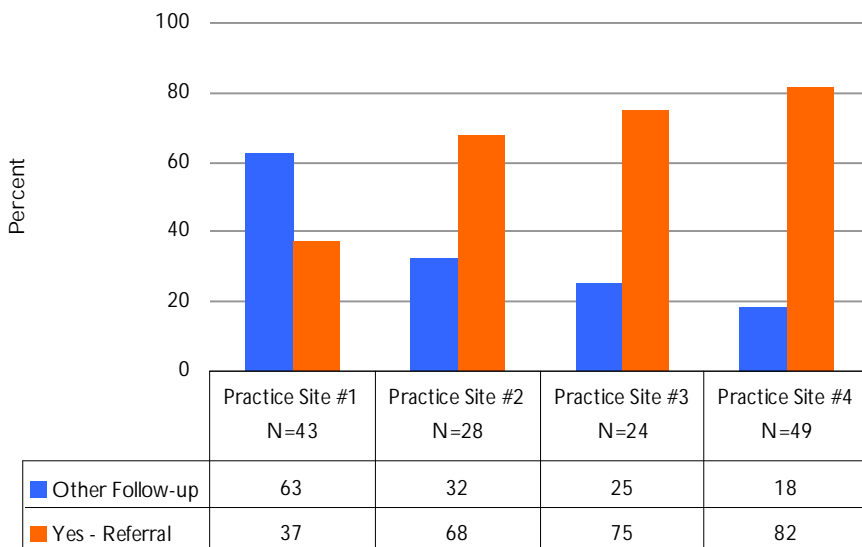
Figure 2.4 details the locations of referrals for the children who were identified as possibly having developmental or behavioral delays. The majority of formal referrals for the post implementation screening group were made to Child Development Watch. Other referrals were made to AI DuPont Hospital for Children, Speech and Hearing, and the School District.

Screening Group - PEDS Specific Analysis

All of the practices referred a larger number of patients for referrals when including non-specific referrals in the proportion of patients identified as possibly having some type of developmental or behavioral delay.

Figure 3.1

Post-Implementation – Referrals Including Non Specific Referrals and Other Follow-up

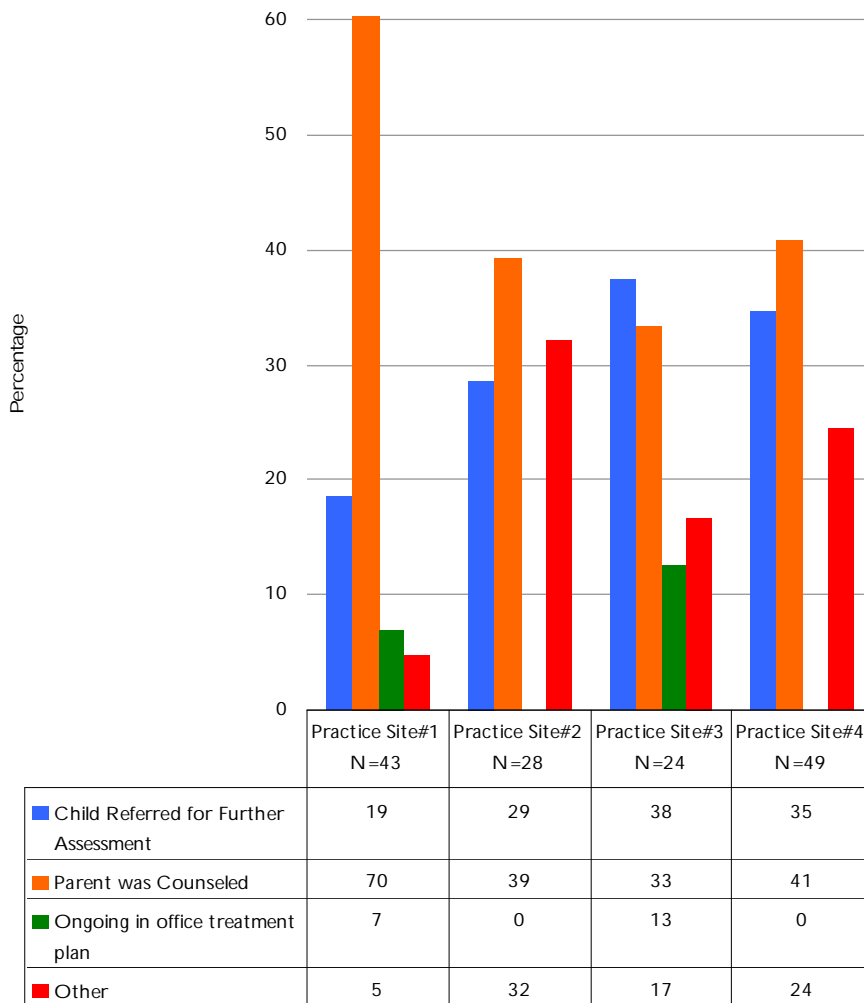


Source: Center for Applied Demography & Survey Research
University of Delaware

Figure 3.1 notes that three out of four practices (**Practice Sites #2, #3 and #4**) formally or informally referred the majority of their patients identified as possibly having a developmental or behavioral delay. Non-specific referral includes those children who were referred for further assessment without additional data on the location to where the referral was made.

Figure 3.2

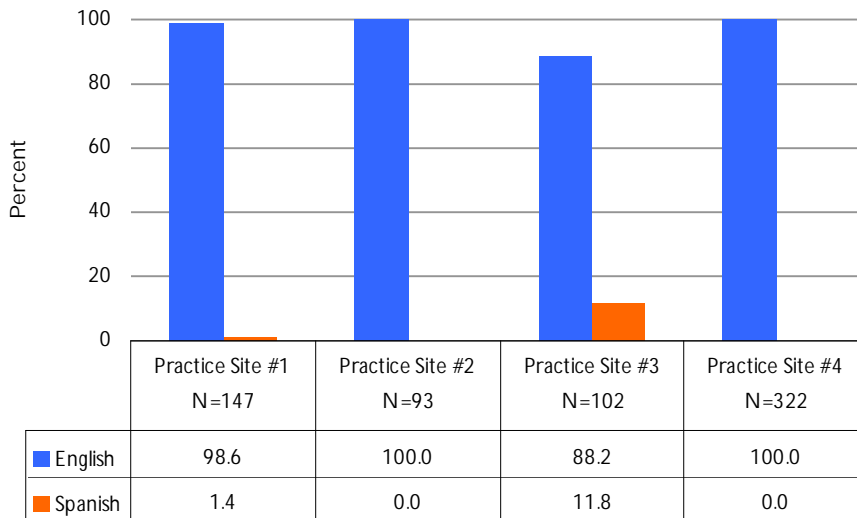
Post Implementation - Types of Follow-up



Source: Center for Applied Demography & Survey Research
University of Delaware

Figure 3.2 highlights the other types of follow-up that were indicated on the patient charts for the children who were identified as possibly having a developmental or behavioral delay. Patients who were identified as having a possible developmental or behavioral delay and referred were also recommended for additional follow-up visits although this chart only highlights referrals other than follow-up visits. For patients who were identified as possibly having a developmental or behavioral delay, practices also recommended non-specific referrals (child referred for further assessment), counseled the parent or recommended ongoing in office treatment plans. (Figure 3.2).

Figure 3.3
Post-Implementation – Language of PEDS tool

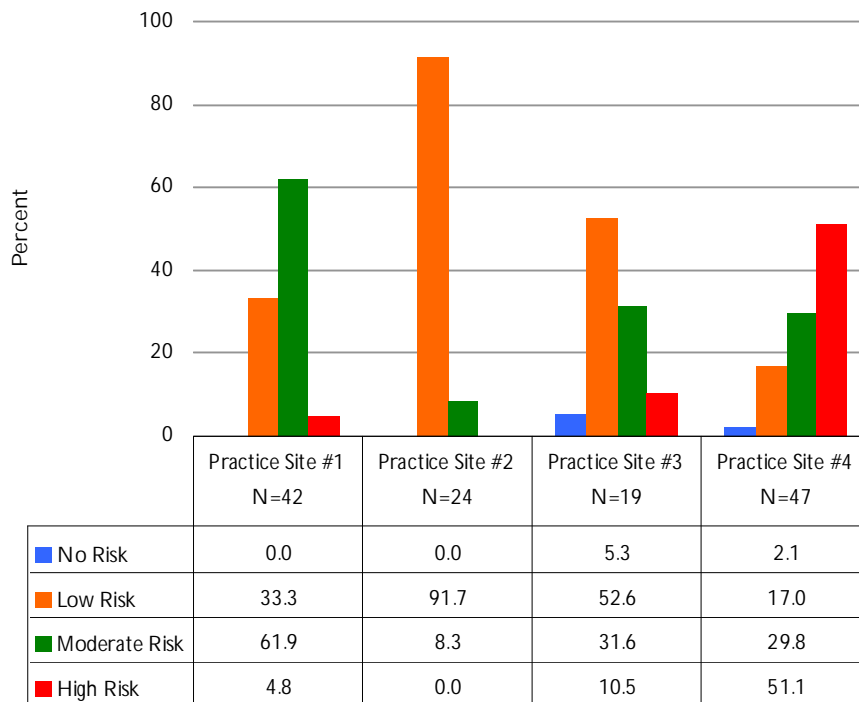


Source: Center for Applied Demography & Survey Research
 University of Delaware

The vast majority of screening group patients among all four of the practices used the English language PEDS tool (Figure 3.3). However, it is interesting to note that about twelve percent of the patients within **Practice Site # 3** used the Spanish language PEDS tool.

Figure 3.4

Post-Implementation – What was the Screening Score?



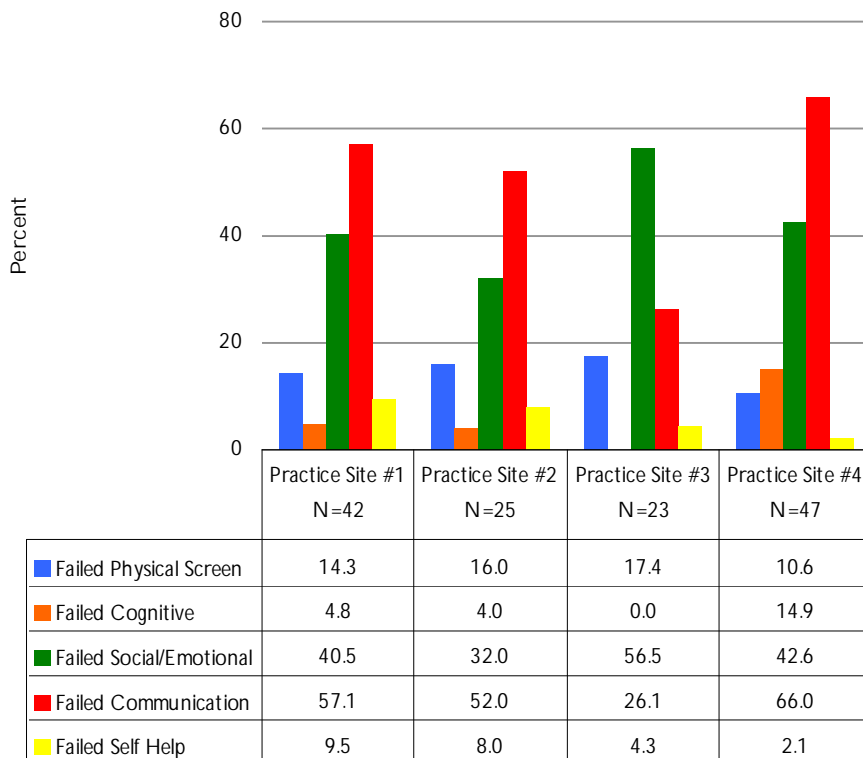
Source: Center for Applied Demography & Survey Research
University of Delaware

Figure 3.4 shows that the screening scores varied widely for all four of the practices with patients who were identified by the PEDS tool as possibly having a developmental or behavioral delay. In **Practice Site #1**, about 62% of the patients who were identified as possibly having a developmental or behavioral delay by the PEDS tool were determined to be at a moderate risk with 33% of the patients considered low risk. The vast majority of patients at **Practice Site #2** were considered low risk (92%) with a very small proportion considered moderate risk (8.3%). Of the patients who were determined to possibly have a behavioral or developmental delay within **Practice Site #3**, the majority (about 53%) were considered low risk while about 32% were considered moderate risk. Finally when reviewing the data for **Practice Site #4**, the majority of patients who were identified as possibly having a developmental delay with the PEDS tool were considered high risk (51%) with about 30% of the patients being considered moderate risk.

When the screening score is evaluated with the PEDS tool, there are a number of different areas that the PEDS tool can identify as an area of delay in the patients development. The following Figure 3.5 looks at the different areas that were evaluated in the PEDS tool to determine if the

patient was at risk for a developmental or behavioral delay. The areas that the PEDS tool identifies as areas of possible developmental or behavioral delay include: physical (gross and fine motor), cognitive, social/emotional, communication and self-help. Some of the screening group patients identified as having a delay with the PEDS tool were identified as possibly having a behavioral or developmental delay in multiple areas.

Figure 3.5
Post-Implementation – Areas Where Patients Failed PEDS



Source: Center for Applied Demography & Survey Research
 University of Delaware

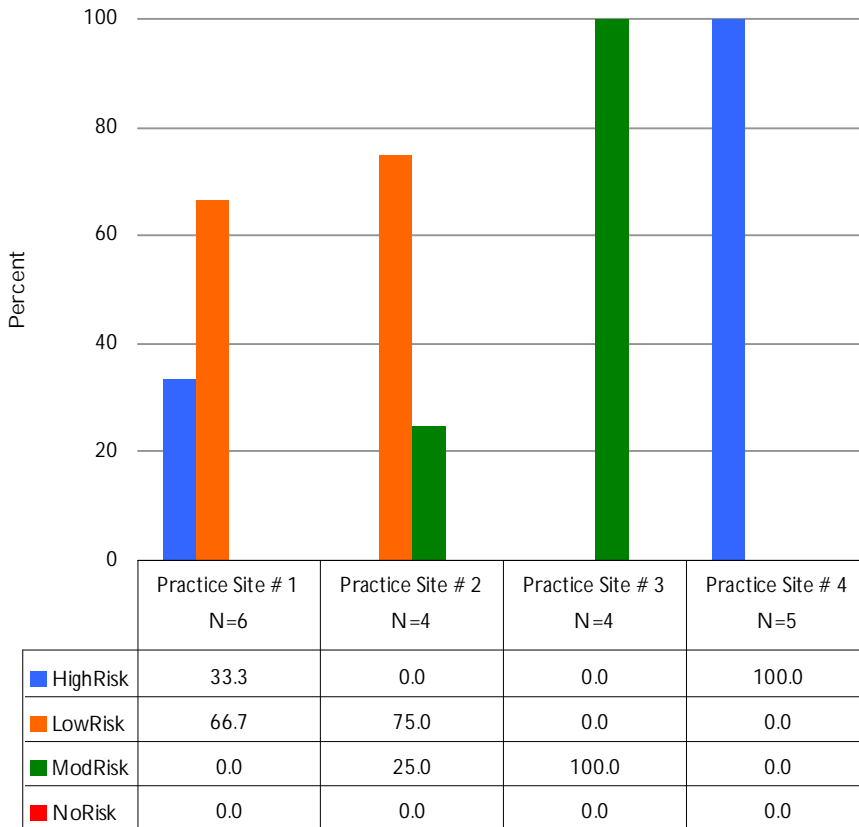
The majority of screening group patients in Figure 3.5 identified as possibly having a behavioral or developmental delay with the PEDS screening tool were identified as delayed in the area of communication. About 66% of the patients in **Practice Site #4** were identified as possibly being delayed in the area of communication with the ranges of communication delay from 26% to 57% for the remainder of the practices. A large proportion of patients identified as possibly being delayed based on the results of the PEDS screen also were identified as possibly being delayed in the area of social/emotional. The proportion of patients identified as possibly delayed in the

social/emotional screen ranged from about 32% in **Practice Site #2** to about 57% in **Practice Site #3**. Of the patients identified as possibly having a developmental or behavioral delay with the PEDS tool, the proportion identified as possibly delayed in physical abilities ranged from about 11% to 17% within all four practices. A significant proportion of the patients identified as possibly being delayed within **Practice Site #4** were delayed in cognitive development (15%). Among the other three practices, the percent of patients identified as possibly delayed in cognitive development ranged from zero to about five percent. Self help delays identified with the PEDS tool was the area having the smallest percentage of patients identified as possibly delayed. The range of patients identified as possibly delayed in self help development ranged from about two percent to ten percent within all practices. The PEDS tool also captured some children who were identified as potentially having developmental or behavioral delays in multiple areas.

The PEDS tool allows for areas of developmental or behavioral delay to be evaluated by level of risk and by type of delay. In Figures 3.6 to 3.10, we looked at level of risk by type of developmental or behavioral delay. Some of the patients were identified as possibly having a delay in multiple areas on the PEDS tool.

Figure 3.6

Post Implementation – What was the screening score by area of risk (Physical)?

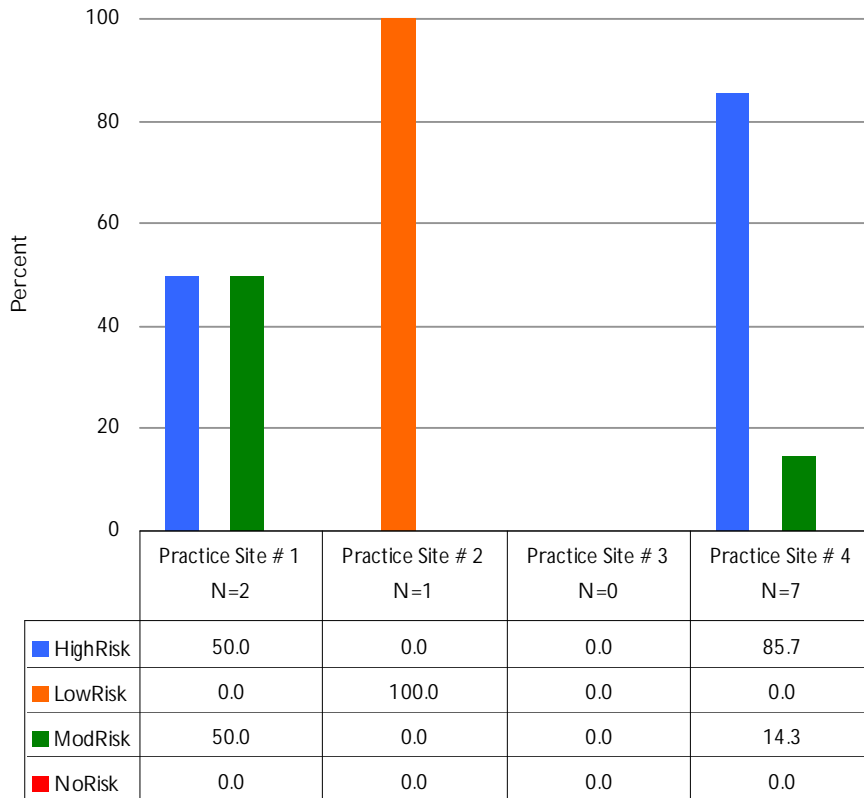


Source: Center for Applied Demography & Survey Research
University of Delaware

When children were identified or flagged for a possible delay on the physical screen, there was considerable variation of the level of risk for each practice site. All of the children treated at **Practice Site #4** and identified as at risk in the physical screen were identified as high risk, while 75% of the patients identified as at risk in the physical screen in **Practice Site #2** were considered low risk (Figure 3.6).

Figure 3.7

Post Implementation – What was the screening score by area of risk (Cognitive)?

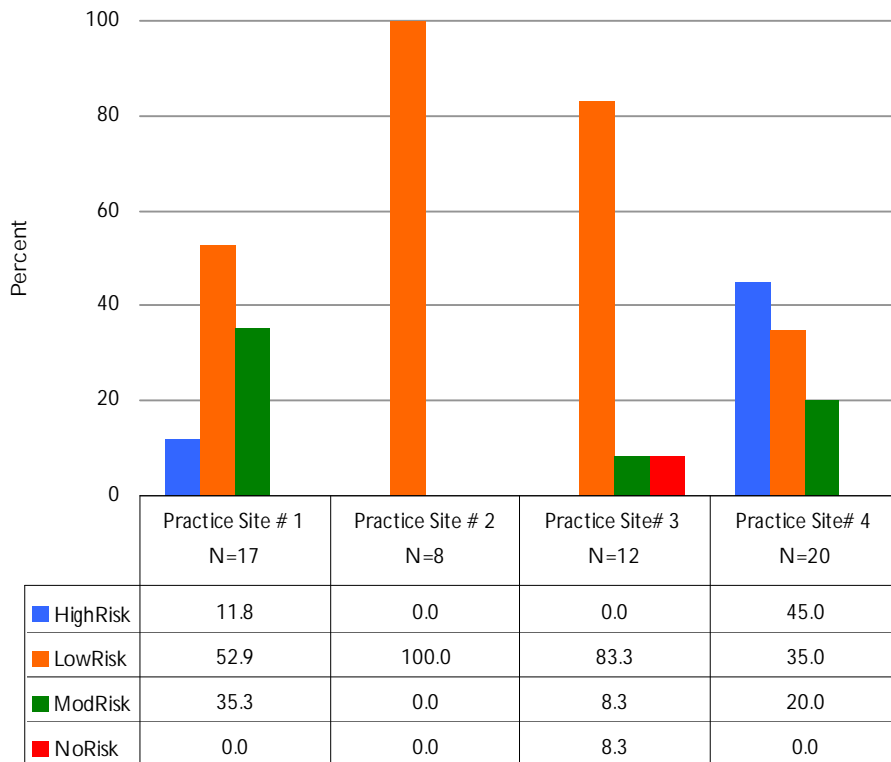


Source: Center for Applied Demography & Survey Research
University of Delaware

Patients identified with a possible delay in the area of cognitive development in Figure 3.8 also varied considerably among all four practice sites with level of risk. All of the patients at **Practice Site #2** identified with a possible delay in the cognitive screen were considered low risk, while 86% of the patients at **Practice Site #4** were identified as high risk.

Figure 3.8

Post Implementation – What was the screening score by area of risk? (Social/Emotional)

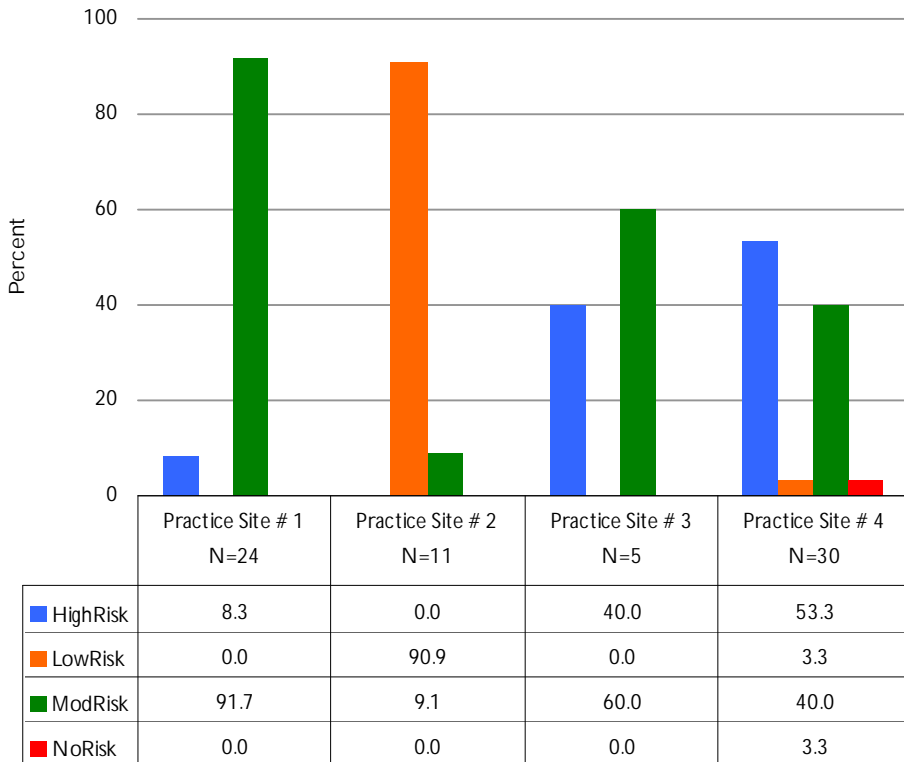


Source: Center for Applied Demography & Survey Research
University of Delaware

All four of the practice sites had patients who had concerns on the social/emotional screen. The area of risk for the majority of these sites varied widely. The majority of the patients where concerns were indicated in the social/emotional screen, were considered low risk (Figure 3.8).

Figure 3.9

Post Implementation – What was the screening score by area of risk? (Communication)

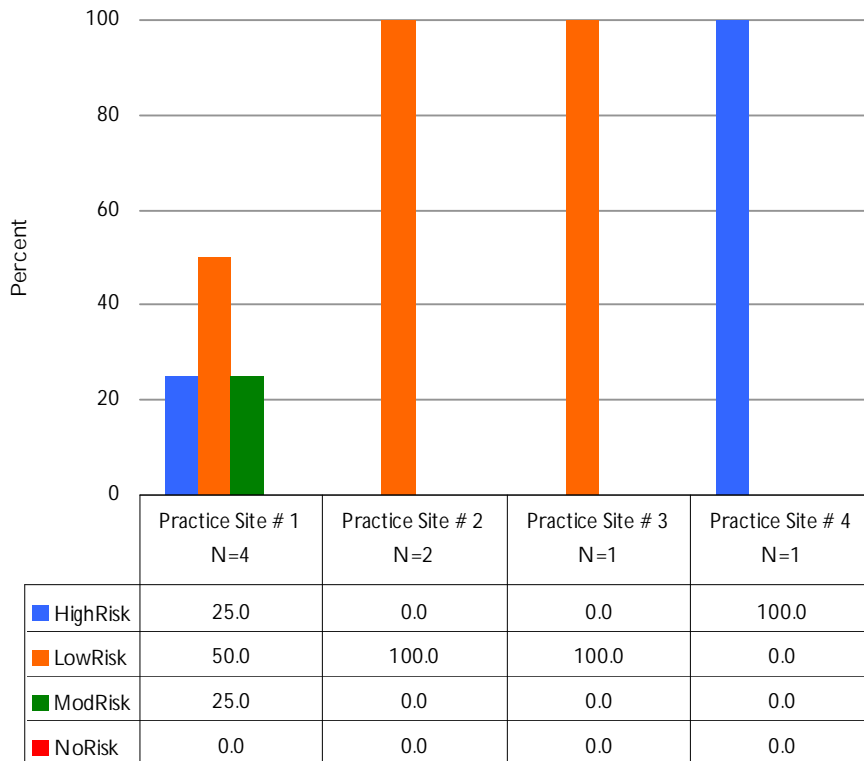


Source: Center for Applied Demography & Survey Research
University of Delaware

In Figure 3.9 the majority of patients at **Practice Sites #1** and **#3** who failed in the area of communication were considered moderate risk (92% and 60% respectively). However, within **Practice Site #2** the majority of patients who failed in the area of communication were considered low risk (91%).

Figure 3.10

Post Implementation – What was the screening score by area of risk (Self-Help)?



Source: Center for Applied Demography & Survey Research
University of Delaware

The majority of the patients who failed the screening for self-help were considered low risk (**Practice Sites #1, #2 and #3**). However, it is interesting to note that 100% of the patients who failed self help in **Practice Site #4** were considered high risk (Figure 3.10).

DISCUSSION

Because we could not assert that any of the data drawn from the four practices was generalizable to the entire state of Delaware or by county, we provided detailed analysis of the data aggregated by practice only and not by county or statewide analysis. Each of the records of both the control group and the screening group were evaluated to determine the number of children that were previously and newly diagnosed with a concern for a behavioral or developmental delay. We evaluated the number of referrals that were made for behavioral and developmental delays prior to and after the implementation of the PEDS tool and where the referrals were made for the children that were determined to need some type of further evaluation for an early intervention program.

Based on our analysis, we found that the use of the PEDS tool identified a higher proportion of children with possible developmental and behavioral delays uniformly across practices. During the project there were significant numbers of children who failed the developmental screening test and were not formally referred to early intervention. Although the majority of children who were not referred were in the low risk range, there were some children who were considered moderate risk and high risk who were not referred. After accounting for non-specific referrals (children who were referred for further assessment without specific data on the location of the referral), the number of patients who were referred dramatically increased. Other than referrals, additional follow-up included ongoing in office treatment or the parent was counseled.

During the course of this research project, there was some initial difficulty recruiting physician practices to participate in the implementation of the PEDS pilot program. The length of time for the control and the screening year had to be reduced to six months from the original time period of eight months due to the delay with recruiting and training the practices. While two practices were initially recruited for the project, one of the first practices later declined to participate; and the process to recruit the other physician practices needed for the pilot program took additional time. Another challenge was the recruitment of practices and communication with office staff during the summer months, when staff and physicians were often out of the office on vacations.

Throughout the project, the implementation of the PEDS tool was a challenge for some of the practices. There was considerable variability with the usage of the PEDS tool among all four of the practices. Cumulative screening rates ranged from 73% to 99% during the six month post-implementation study period. It took more time in some practices than others for the nurse

educators to build relationships with the provider office staff and effectively integrate the screening tool into each practice's unique workflow.

There was a variety of reasons the practices had difficulty implementing the utilization of the PEDS tool. Some of the challenges included the season during which the project took place. The fall/winter months are customarily flu season and during the implementation of the PEDS tool the H1N1 flu began to significantly affect pediatric practices. The advent of the both the flu and H1N1 made it difficult for some of the practices to juggle conducting the developmental screening and maintaining attention to the needs of patients during an increased number of sick child visits.

APPENDIX A

CASE STUDIES FOR EACH PILOT SITE

Four sites were selected for the case studies to determine if more children were identified with a possible developmental delay before the implementation of the screening tool than after the implementation of the screening tool. The characteristics of each practice vary with the four practice sites highlighted individually.

Practice site #1 -

Practice site #1 is a small practice with a total of one physician and nine other employees. This practice is located in Sussex County. This practice primarily accommodates pediatric patients with the practice having a total of about 4000 patients. Patient volume is about 640 patients per month. The majority of these patients are covered under private insurance; about twenty-five percent utilize Medicaid, and the remainder of the patients are self-pay. Well-child visits are regularly conducted at 9, 18, 24 and 36 months in addition to a variety of other routinely scheduled well-child visits.

Practice site #2 –

This practice located in New Castle County is made up of three physicians, along with seven other practice staff and two additional office staff. This practice serves approximately 60 to 100 patients per day, depending on how many doctors work on that day. About three quarters of the patients use private insurance while the majority of the remainder are covered by Medicaid. This practice conducts well-child visits at one week, one month, two months, four months, six months, 12 months, 15 months and 18 months.

Practice site #3 -

This is a small office with one physician, four full time employees and one part time employee. This office gets about 350 to 400 visits per month. The majority of patients who utilize this practice are Medicaid recipients with most of the remainder of the patients utilizing private insurance. Well-child visits are conducted during varying intervals including 9 months, 18 months 24 months and 36 months. This practice is located in Sussex County, Delaware.

Practice site #4 -

This practice has two locations - one in Kent County and the other in New Castle County, Delaware. Pediatric patients are the primary patients at this practice, and patient volume is a little more than 1500 patients per month. About half of the patients at this practice are covered by private insurance with the remainder of the patients utilizing Medicaid or self-pay. Well-child visits are conducted at this site during 9, 18, 24 and 36 months in addition to a variety of other routinely scheduled well-child visits.

APPENDIX B

Pre-Implementation Data Collection Method by Practice -

Date ranges March 15, 2009 – September 13, 2009 (9, 18, 24 and 36 month well-child visits)

Practice Site # 1 -

The billing person for this practice was unable to use the billing data to select the patients. This individual determined the appropriate range of birthdates for the 9, 18, 24 and 36 month visits during the specified time period. She then drew this range of patients with the appropriate birth dates out of the patient database.

Due to an initial error in selecting the time period for the pre- implementation data pull, we had to re-do the random selection of this practice with 125 new uniquely identified patients. After pulling **Practice Site #1** data, we found that many of the patients that were listed as current were actually patients that had just been seen at birth in the hospital by the provider in this practice. Those patients seen only at the hospital were not included in the study. Due to the large number of these cases we pulled an additional 35 unique patient ID numbers from the patients selected from the second sample of patients provided by the nurse educator to more closely match the pre- implementation group size of the other practices. We were unable to analyze 38 out of the total 125 patient charts pulled; therefore, we had to randomly select additional unique ID numbers a third time using SPSS. The third time that we randomly selected patient ID numbers the nurse pulled 60 charts for **Practice #1** to compensate for the expected patient charts that we would be unable to use. We were then able to exclude 27 of the original 38 of the patient data collection tools that were not able to be analyzed. Many of the complications experienced with **Practice #1** were because this site was primarily paper-based and there was no way to initially excluded patient charts that were not eligible for analysis.

Practice Site # 2 –

One of the first practices selected for the project later declined to participate and was replaced with **Practice Site #2**. Due to the last minute change with the practices we were not able to begin collecting data at the same time as the other three practices. While we looked at the same pre-implementation date ranges as for the other practices (March 15 – September 13), the post-implementation data collection experienced a delay of about three or four weeks. For the pre-implementation process the selection of the pre- implementation list was done by a historical search of the well-child visits in the practice management system. This search was done for well-child visits for children who were 8 to 11 months of age, 17 to 20 months of age, 23 to 26 months of age and 34 to 37 months of age.

Practice Site #3 -

The staff of the provider for this practice site printed off all of the appointment sheets for the six month pre-implementation data collection period. The nurse educator then went over each sheet and identified the patients that were seen for the 9, 18, 24 and 36 month well-child visits. After the children were identified for their respective well-child visits, the nurse educator then looked up birthdates and gender of each of the patients for the purpose of data collection.

Practice Site #4 –

The pre-implementation process utilized an electronic method to gather the names of the patients for the 9, 18, 24 and 36 month birth dates. The practice utilized this method to do an electronic query of the patients seen during the March 15, 2009 – September 13 date range.

After analyzing the first 125 randomly selected patients, we determined that 24 of the patients selected could not be used for analysis because they had either transferred out of the practice or were no shows to their appointments. Due to this high number of missing patient data, we had to randomly select additional patient ID numbers. In this case, we randomly selected an additional 25 charts to compensate for the patient charts that could not be used for analysis.

APPENDIX C**Post-Implementation Data Collection Method by Practice -**

Date ranges September 14, 2009 – March 12, 2009 (9, 18, 24 and 36 month well-child visits)

Practice Site #1 -

This practice kept a list of the patients who attended their 9, 18, 24 and 36 month well-child patients for the week. The designated office staff in the practice then physically pulled each chart of the children who attended the well-child visits and provided that chart to the nurse educator to complete the data collection.

Practice Site #2 –

Although post-implementation was supposed to begin in September, it was delayed with this practice because it was selected to participate at a later date than the other participating sites. The actual implementation date of the PEDS tool was as late as October 22, 2009. The method that this practice used to identify the patients who attended the well-child visits prior to December 7 was the following. The billing list was pulled by the nurse educator. The children who came to the doctor for a well-child visit were listed with a double entry on the billing list as opposed to a single entry for sick child visits. The billing list did not include any identifiers, such as birth date.

After December 7, the nurse educator was provided with a daily schedule that also listed the well-child visits. This daily schedule included identifiers and also included the birth date of the child. The inclusion of the birth dates on the daily schedule meant that even if the nurse was not able to recover the chart, she was able to keep track of what patients she was not able to get chart information for that should have been included based on their birth dates.

As previously noted, prior to December 7 when the billing list was used, the nurse educator did not have the patients' birth dates. If a patient chart was not on the shelf before December 7, there was no way to keep track of whether or not a child should have been included based on their birth date. Once the daily schedule was provided, the problem of not being able to keep track of the charts was resolved. When the daily schedule was not provided during some days after December 7, some of the patients who should have been included could have been missed if the chart was not found in the files. Since their birth date was unknown, the nurse educator would assume the chart was filed in a separate area for the older children.

In the first month of the project, the nurse educator for **Practice Site #2** was just receiving the completed PEDS tool from the provider. This meant that if there were children who came in for their well-child visit and were not being screened, then they were not caught as having a missed screening during their well-child visit. This problem was discovered on October 22 and should have no reflection on the presented data.

Practice Site #3 -

The physician in this practice kept track of the patients by name based on which children attended the well-child appointments for 9, 18, 24 and 36 months. This list of patients who attended the well-child visits was provided to the nurse educator and she then pulled the patient charts based on the names provided by the physician.

Practice Site #4 –

The nurse educator reviewed the patient appointment log each day at the physician's practice and pulled the 9, 18, 24 and 36 month visit charts to gather the necessary information for

the data collection tool. This practice experienced some difficulty with the implementation and consistent usage of the PEDS tool. Some of the difficulties were likely because of staff turnover during the project period and the fact that H1N1 and the flu season took place during the same time of this study's implementation.

APPENDIX D

PEDS Project Chart Review
Delaware Pilot Study (Pre Project Implementation)

ID #

Month of Screening

Date of Abstraction_____

Provider_____

I. Demographic Information

Date of Birth: _____

Sex: Male Female

Date of Visit:_____

Insurance Type:

Medicaid

Private Insurance

Patient Pay

Other: Explain

Ethnicity: Hispanic

Non-Hispanic

Race: White

Black

Other

II. Screening

1. Did a developmental screening take place for the month of screening identified above?

Yes (proceed to question 2)

No (stop)

2. Was a developmental or behavioral delay identified?

Yes (proceed to question 3)

No (Stop)

3. Was a referral made for a developmental or behavioral delay?

Yes

No

4. Where was the referral made to if a referral was made for a developmental or behavioral delay?

APPENDIX E

**PEDS Project Chart Review
Delaware Pilot Study (Post Project Implementation)**

ID #

Month of Screening

Date of Abstraction_____

Provider_____

I. Demographic Information

Date of Birth: _____

Sex: Male Female

Date of Visit:_____

Insurance Type:

Medicaid

Private Insurance

Patient Pay

Other: Explain

Ethnicity: Hispanic

Non-Hispanic

Race: White

Black

Other

II. Screening

1. Did a developmental screening take place for the month of screening identified above?

Yes (proceed to question 2)

No (stop)

2. Was a developmental or behavioral delay identified?

Yes (proceed to question 3)

No (Stop)

3. Was a referral made for a developmental or behavioral delay?

Yes

No

4. Where was the referral made to if a referral was made for a developmental or behavioral delay?

PEDS Specific Questions

5. What was the screening score (circle one)?

- a. High risk
 - b. Moderate Risk
 - c. Low Risk
 - d. No Risk
- (if missing go to 7b)

a. Area(s) failed: Physical (gross and fine motor) Cognitive
 Social/Emotional Communication Self Help
(go to 6)

a. If missing, reason for missing score:

6. Please circle any of the following noted in the chart:

Scheduled follow-up visit Child referred for further assessment

Parent was counseled Child referred for treatment

The issue was addressed during the visit through the following:

Parent given activity sheets and/or brochures

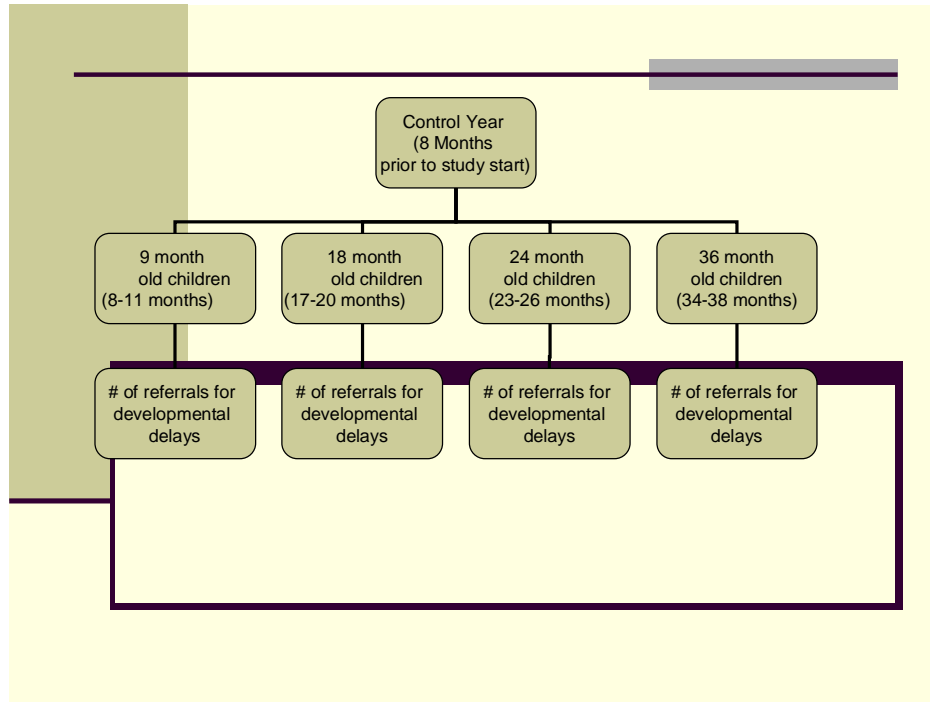
Ongoing in-office treatment plan was devised

Other: Explain

None of the above: Explain

APPENDIX F

Control Year



Screening Year

