The Role of Developmental Screening Practices in Early Diagnosis of Autism Spectrum Disorders: An Analysis of All-Payer Claims Data in New Hampshire

Betsy P. Humphreys

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Approved by:
Samuel L. Odom
Rebecca S. New
Elizabeth R. Crais
Karen Erickson
Harriet Able
Monica McClain
ABSTRACT

BETSY P. HUMPHREYS: The Role of Developmental Screening Practices in Early Diagnosis of Autism Spectrum Disorders: An Analysis of All-Payer Claims Data in New Hampshire
(Under the direction of Samuel L. Odom, Ph.D.)

Universal developmental screening during pediatric well child care detects early delays in development and is a critical gateway to early intervention for young children at risk for Autism Spectrum Disorders (ASD). Developmental screening practices are highly variable, and few studies have examined screening utilization for children at risk for ASD. Currently, a two to four year gap exists between first recognition of concern and referral for diagnostic evaluation of ASD. The purpose of the current study was to examine the influence of developmental screening practices on timing of ASD diagnoses in the state of New Hampshire through health care administrative claims data from the New Hampshire Comprehensive Health Care Information System. The study examined differences in mean age of ASD diagnosis for a sample of 144 children who were born between January 2007 and December 2010 who received or did not receive universal screening during well child care, as well as those who received screening at multiple time points and those who received screening at one time point. Further, the study examined the association between gender, geographic region and provider type on age at diagnosis of ASD. The data suggested no significant differences in mean age of ASD diagnosis for children who received a standardized developmental screening during well-child care and those who did not.
Statistically significant differences in mean age of diagnosis were found between children who were screened at one time point and children who were screened at more than one time point. Children screened at more than one time point were diagnosed later than those screened at one time point. Geographic region was a significant predictor on age of ASD diagnosis accounting for approximately 31% of the variance. Continued efforts to measure screening practices through use of administrative claims data may increase utilization and improve access to intervention for young children at risk for ASD.
ACKNOWLEDGEMENTS

The relationship between early childhood education and pediatric primary care is intriguing, as both are intimately involved with young children during a period of rapid development. The potential for mutually beneficial partnerships exists, yet there are few opportunities for the two service sectors to collaborate. This dissertation has afforded me the opportunity and challenge of studying, questioning, and developing an understanding of the issues related to timely early intervention through developmental screening in pediatric primary health care for young children with ASD.

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CHAPTER 1

Autism spectrum disorder\(^1\) (ASD) is a neurodevelopmental disorder characterized by differences in social interaction, communication, and repetitive and stereotyped patterns of behavior (Diagnostic and Statistical Manual of Mental Disorders-IV-TR; American Psychiatric Association, 2000). ASD is a heterogeneous disorder disrupting development across multiple domains at different rates during the first two to three years of life (Dawson, 2008; Rogers, 2009; Tager-Flusberg, 2010). Once considered a rare disorder, ASD is now considered the fastest growing developmental disability in the United States. Recent prevalence estimates suggest 1 in 110 children are affected by the disorder (Van Naarden, K. et al., 2007) with males diagnosed four times more frequently than females (Fombonne, 2009). At the present growth rate, the cost to society in the next decade is estimated at $200-400 billion annually. However, with early diagnosis and intervention these costs may be reduced by as much as two-thirds (Ganz, 2007).

To date there are no biological markers for identification of ASD. However, early expression of ASD includes the gradual loss of typical social and communication behaviors, as well as the gradual emergence of atypical ones (Colgan et al., 2006; Ozonoff et al., 2010). Developmental differences, not evident at six months of age, may appear gradually between nine and twelve months of age with distinct behavioral markers of ASD observable by twelve months (Baranek, 1999; Brian et al., 2008; Bryson et al., 2007; Colgan et al., 2006; Landa,

\(^1\) The term Autism Spectrum Disorder (ASD) will be used throughout this paper to describe Autistic Disorder, Asperger’s Disorder and Pervasive Development Disorder-Not Otherwise Specified.
Holman, & Garrett-Mayer, 2007; Maestro et al., 2005; Osterling & Dawson 1994; Osterling, Dawson & Munson, 2002; Ozonoff et al., 2008; Ozonoff et al., 2010; Zwaigenbaum, 2005). Infancy and early childhood are sensitive periods for intervention; some scholars suggest that intervention during this period may prevent full expression of a mental health disorder (Fonagy, 1996; Dawson, 2008). For young children with ASD, early and intensive behavioral intervention has the potential to significantly improve outcomes in IQ and adaptive functioning (Dawson et al., 2010; Kasari, Freeman, & Paparella, 2006; McGee, Morrier & Daly, 1999; Reichow, 2012; Warren et al., 2011; Woods & Wetherby, 2003). The prevalence of developmental disabilities in children (3-17 years) in the United States is estimated to be over 15%; however, the Annual Report to Congress (2008) indicated that less than half of children ages 3-to-5 received early childhood special education. The pathway from early detection of developmental risk to early intervention is a protracted one, which requires the coordinated efforts of professionals from multiple disciplines and service sectors over a period of years.

Most pathways include a combination of the following activities: early developmental screening and detection of risk factors, referral from primary care, early intervention eligibility evaluation, and diagnostic evaluation (Volkmar, Cook, Pomeroy, Realmuto, & Tanguay, 1999; Filipek et al., 2000; National Research Council, 2001; Zwaigenbaum 2009; Lord & Bishop, 2010). The combination and coordination of activities that is typically required delays children from receiving the long-term benefits of early intervention during a critical period in their development.

Parents are often the first to recognize concerns about their infants during the first 12-18 months of life (DeGiacomo & Fombonne, 1997; Ozonoff et al., 2009; Rosenberg et al,
2011). However despite parent recognition of early warning signs, and emerging evidence that ASD can be reliably diagnosed between two and three years of age (Charwarska, Klin, Paul, Macari & Volkmar, 2009; Lord et al., 2006; Risi et al., 2006), the mean age of diagnosis continues to be between five and six years (Mandell et al., 2010; Shattuck et al., 2009). Factors influencing age at diagnosis may include gender, race, socioeconomic status (Fountain, King & Bearman, 2010; Shattuck et al., 2009; Mandell et al., 2009), access to health care, geographic location, and type of ASD diagnosis (Rosenberg et al., 2011). This results in a two to four-year gap between recognition of early behavioral markers and diagnosis of ASD.

In the past decade, the prospects of identifying infants and toddlers at risk for ASD and providing early and intensive intervention have improved. Public health awareness campaigns such as the Centers for Disease Control and Prevention’s Learn the Signs Act Early Campaign (Centers for Disease Control and Prevention, 2012) have successfully promoted primary and secondary prevention measures for young children with ASD. Practice parameters for the identification, diagnosis and care of young children with ASD in primary care, neurology and psychology (Volkmar et al., 1999; Filipek et al., 2000; Johnson & Myers, 2007) have been developed and are widely used across disciplines. Concurrently, due to the persistent efforts of early childhood professionals and researchers, an evidence-base for early and intensive behavioral intervention for children with ASD has begun to emerge (Dawson et al., 2010; Reichow, 2012). These represent important first steps toward early identification of the disorder. However, continuing to improve early identification of young children at risk for ASD will require better coordination among primary care, specialists in neurology and psychology, and early childhood professionals.
Pediatric primary health care plays an important role in the identification of young children at risk for ASD. Throughout the past decade, the role of the pediatric provider\textsuperscript{2} in screening for developmental delays, including ASD, has been the source of a great deal of attention. Pediatric providers are scheduled to see young children at frequent intervals through the first 3 years and have the capacity to promptly identify potential problems or delays in child development. Further, pediatric primary care guidelines recommend the use of some type of standardized developmental screening instruments and ASD-specific screening instruments at specific ages. Young children at risk for ASD are likely to experience early delays in one or more domains of development (Charwaska, Klin, Paul & Volkmar, 2007; Fombonne, 2005) and the consistent use of standardized developmental screening tools has the potential to accelerate the path to intervention for this population.

Numerous barriers to the implementation of general and ASD-specific screening guidelines have been identified, which influence the timing of ASD diagnoses and access to educational and health care services (Mandell et al., 2010; Shattuck et al., 2009). Pediatric care providers cite time constraints (Jarbrink & Knapp, 2001; Schor, 2004; Dosreis, Weiner, Johnson & Newschaffer, 2006), discomfort making a formal referral for autism (Jacobsen & Mulick, 2000), limited reimbursement for screening visits (Schor, 2004; King et al., 2005; Golnick, Ireland & Borowsky, 2009), a lack of familiarity with screening tools (Dosreis et al., 2006; Tanner, Stein, Olson, Friintner & Radecki, 2009), and inadequate training in child development (Schor, 2004) as reasons for not following the recommended screening guidelines. Some providers fear labeling a child too early (Happe & Frith, 1991) and cite inadequate referral sources (Tanner et al., 2009). Other barriers to screening are related to

\textsuperscript{2} The term pediatric provider will be used throughout this paper to refer to pediatricians, family practice physicians, pediatric nurse practitioners and pediatric physician assistants.
such factors as race, ethnicity, socioeconomic status and geographic region, which are reflected in timing of ASD diagnoses and access to educational and health care services (Mandell et al., 2010; Shattuck et al., 2009). Improving the utilization of standardized developmental screening tools during the early years requires a comprehensive understanding of practice guidelines in pediatric primary care and an examination of system and practice barriers affecting families, health care providers, and early intervention professionals.

The current study examined the influence of developmental screening practices on timing of ASD diagnoses for young children in the state of New Hampshire through health care administrative claims data from the New Hampshire Comprehensive Health Care Information System. To provide background for understanding the methods and results of the investigation, an overview of current universal, ASD-specific, and mental health screening guidelines and practices in pediatric primary care are described followed by key demographic information and other characteristics of the state of New Hampshire. Barriers associated with recommended practices, as well as the practical and ethical implications of early diagnosis from the perspectives of parents and providers are then described.

**Guidelines for Early Detection of Developmental and Behavioral Disorders**

The expectation that pediatric primary care providers screen for a range of developmental and behavioral disorders has increased significantly in the past decade. Since 2006 the American Academy of Pediatrics (AAP) has published three sets of practice guidelines for early detection of developmental and behavioral disorders (birth to 5 years). These include universal developmental surveillance and screening (AAP Council on Children with Disabilities, 2006), ASD-specific surveillance and screening (Gupta et al., 2007; Johnson & Myers, 2007), and social-emotional surveillance and screening (Foy & AAP Task
Yet, few studies have examined these guidelines and the implications of their use for young children at risk for ASD.

The American Academy of Pediatrics (AAP) *Recommendations for Preventive Pediatric Health Care* (AAP, 2008) suggest six routine well-child visits for children birth to one year, and four visits during the second year. Beginning at age two well-child visits occur annually. Comprehensive health evaluation during well-child visits includes taking history, growth measurements, screening vision and hearing, immunizations, laboratory screening processes (e.g., newborn metabolic, lead, tuberculin) and developmental/behavioral assessment (AAP, 2008).

**Universal Surveillance and Screening**

Routine developmental surveillance has historically been a part of pediatric preventive care. However in 2006, the American Academy of Pediatrics (AAP) expanded their developmental surveillance and screening guidelines, identified crucial components of surveillance, and recommended that surveillance be conducted at every well-child visit (AAP, 2006). Universal developmental surveillance is now defined as a “longitudinal, continuous and cumulative process” (AAP, 2006, p. 407) used to identify children at risk for developmental delays and disabilities.

Guidelines identify five distinct components of surveillance that should occur prior to or during well-child care. These include: (a) eliciting and attending to parents’ concerns, (b) probing age-appropriate skills in each domain through parent report and observation of the child, (c) maintaining a developmental history, (d) identifying risk and protective factors, and (e) documenting findings. Developmental surveillance is a fluid and continuous process, highly dependent on the quality of the relationship between parent and provider, and is
estimated to detect 20-40% of children with developmental disabilities (Glascoe, 2000; Sand et al., 2005). Immediate follow-up with a standardized developmental screening tool is recommended at the first sign of risk (AAP, 2006; Johnson & Myers, 2007; Gupta et al., 2007). Developmental surveillance is supported by developmental screening, which is a broad-based strategy used in well-child care.

The periodicity schedule for developmental screening recommends use of a standardized screening tool at 9-, 18-, and 30- months; however, if a 30-month visit is not part of the pediatric practice, then screening at 24-months is recommended (AAP, 2006). Young children at risk for ASD are likely to experience early delays in one or more domains of development (Charwaska et al., 2007; Fombonne, 2005) and 75-80% of children with ASD experience co-morbid behavioral or physical health disorders (Sheldrick & Perrin, 2010). Periodic use of standardized developmental screening instruments, paired with careful assessment of parents’ concerns, has the potential to assist in early detection of developmental and behavioral disorders and accelerate the path to intervention for young children at risk for ASD (Caronna, Augustyn, & Zuckerman, 2007; Glascoe, 1999; How, Fryer, McCarthy, Schoen & Schor, 2011; Squires, Nickel, & Eisert, 1996).

An analysis of data from the National Survey of Children’s Health (Bethell, Reuland, Schor, Abrams & Halfon, 2011; N=24 million) demonstrated that the odds of a child between the ages of one and five years being enrolled in early intervention and having an Individualized Family Service Plan (IFSP) were 2.41 times more likely if an AAP-recommended, parent-completed, standardized developmental screening tool was completed during well-child care. Children under 36 months at high risk for a developmental or behavioral disorder were three times more likely to have an IFSP when developmental
screening was completed (Bethell, Reuland, Schor, Abrams & Halfon, 2011). Thus, the consistent use of standardized developmental screening tools in primary care increases timely access to early and intensive behavioral intervention at the first sign of concern. This is especially critical for young children at risk for ASD who have shown significant improvements in IQ and adaptive functioning when intervention occurs between 18 and 30 months of age (Dawson et al., 2010).

**Adoption of universal screening guidelines.** National estimates suggest that between 50% and 75% of pediatric providers utilize standardized developmental screening instruments during well-child care (Arunyanart et al., 2012; Radecki, Sand-Loud, O’Connor, Sharp & Olson, 2011; Sand et al., 2005; Sices, Feudtner, McLaughlin, Drotar & Williams, 2004). Recently, the Commonwealth Fund State Scorecard on Child Health System Performance reported that one in five children under the age of five years received a developmental screening in the United States in 2007 (How et al., 2011). A comparison of findings from the AAP’s Periodic Survey of Fellows suggests that the number of pediatricians using one or more screening tools during well-child care increased from 23% in 2002 to over 47% in 2009 (Radecki et al., 2011). However, approximately half of the pediatricians surveyed used informal checklists or documentation of parent concerns, rather than a standardized developmental screening instrument. These findings are supported by data from the 2009-2010 National Survey of Children with Special Health Care Needs (n = 4,375) where sixty-three percent of parents responded that their child (12 months to 5 years) had not received a developmental screening in the previous 12 months (described as a questionnaire about their child’s development, communication or social behaviors) (Data Resource Center for Child and Adolescent Health, 2011). For young children at risk for
ASD this low utilization of standardized developmental screening instruments has critical implications. More consistent utilization of standardized developmental screening tools in primary care could improve early identification of developmental risk factors and allow access to early and intensive behavioral intervention well in advance of an ASD diagnosis.

The increased prevalence of ASD in the last decade prompted several national organizations to publish ASD-specific surveillance and screening guidelines for differentiating children who are at risk for ASD from typically developing children, and from those with other developmental delays and disabilities.

**ASD-specific Surveillance and Screening**

Practice parameters specifically for screening, assessment and diagnosis of ASD were first published by the American Academy of Child and Adolescent Psychiatry (Volkmar et al., 1999) and the American Academy of Neurology (AAN; Filipek et al., 1999), followed shortly thereafter by the guidelines for treatment of ASD in primary care by the American Academy of Pediatrics (AAP, Committee on Children with Disabilities, 2001). In 2007 the AAP expanded and revised its ASD-specific guidelines in their clinical report entitled “Identification and Evaluation of Children With Autism Spectrum Disorders” and included a developmental surveillance and screening algorithm for pediatric well-child visits (Johnson & Myers, 2007). These documents provide the foundation for current practice across the disciplines of psychiatry, neurology and primary care, and also assist diagnostic clinicians and primary care providers in identifying and providing treatment for children at risk for ASD.

Practice guidelines specify three risk factors: (a) family history of ASD, (b) parent or caregiver concerns about early developmental milestones, especially in the area of social
communication, and (c) provider concerns. Additionally, four observable behaviors warranting immediate diagnostic evaluation include: (a) no babbling or pointing or other gestures by 12 months, (b) no single words by 16 months, (c) no two-word spontaneous phrases by 24 months, and (d) loss of language or social skills at any age (Filipek et al., 1999; Gupta et al., 2007; Johnson & Myers, 2007). Surveillance and screening guidelines emphasize that providers should never delay referrals for developmental evaluations and services if there are concerns (Johnson & Myers, 2007; Caronna et al., 2007).

There are two approaches to ASD-specific developmental screening. The AAP guidelines suggest that a population-based screen (Level 1) such as the Modified Checklist for Autism in Toddlers (MCHAT; Robins, Fein, Barton, & Green, 2001) be administered in conjunction with a universal screening to all children at 18- and 24-months, and further evaluation with a specialized ASD-specific screen (Level II) if initial screening is indicative of risk. Referral for immediate diagnostic evaluation is recommended if initial screening is indicative of risk (Gupta et al., 2007; Johnson & Myers, 2007). By contrast, the AAN practice parameters recommend the use of more specific Level II screens after a general developmental screen indicates a risk of ASD. The AAN does not advocate the use of population-based (Level I) ASD screening instrument (Filipek et al, 2000). Level II screening tools generally require more time to administer and more expertise on the part of the primary care provider to score and interpret. These tools are typically used in specialized settings where children with known developmental delays are referred, such as a neurology clinic or early intervention agency (Bishop, Luyster, Richler & Lord, 2008; Johnson & Myers, 2007). Inconsistencies in AAP and AAN practice guidelines may be negatively influencing clinical practice in preventive pediatric care and is worthy of further investigation.
Adoption of ASD screening guidelines. A number of studies have examined prevalence estimates across states (Center for Disease Control and Prevention, 2012; Liptak et al., 2008) and regional differences in identification of ASD (Mandell & Palmer, 2005). However, there is a significant gap in the literature on utilization of ASD-specific screening in primary care. For example, a comparison of survey responses (n - unpublished) after the Learn the Signs Act Early Campaign was implemented in 2006 reported that pediatricians were more aware of resources for referral and treatment (87%), and had resources to educate parents (77%) (Daniel, Prue, Taylor, Thomas & Scales, 2009). However, nearly 20% of pediatricians continued to employ a ‘wait and see’ approach for young children at risk for ASD (Daniel, Prue, Taylor, Thomas & Scales, 2009).

Arunyanart et al. (2012) surveyed pediatricians and nurse practitioners in six states (n = 480) and reported unexpected disparities in access to screening practices based on geographic, socioeconomic and demographic factors. In their sample, providers in urban settings serving high percentages of Medicaid-enrolled families were more likely to conduct developmental and autism-specific screenings than providers in suburban settings serving high percentages of privately insured, White families and lower percentages of non-White, Medicaid-enrolled families. Seventy-five percent of respondents reported using a standardized ASD-specific screening tool.

Other studies at the state level include a sample of 54 providers in two southern states (Alabama and Mississippi) who reported use of ASD-specific screens at 28% (Gillis, 2009) and a sample of 255 primary care physicians from the Mid-Atlantic region where only 8% of the physicians used ASD-specific screening tools (Dosreis et al., 2006). Clearly, further study of ASD-specific screening instrument utilization in primary care is warranted.
Social-emotional Surveillance and Screening

In 2010 the AAP Task Force on Mental Health published a comprehensive supplement on pediatric mental health (Foy & AAP Task Force, 2010). Although this exists as a separate set of guidelines, the document subsumed universal and ASD-specific guidelines for surveillance of children under 5 years of age. The algorithm specifies procedures for identifying social-emotional concerns in early development and recommends referral for further evaluation when any of the following conditions are present: “disordered parent-child relationship, parental mental illness, language or communication delay (emphasis added), disruptive behavior with aggression, abuse or neglect of the child, and self-injury” (Foy & AAP Task Force, 2010; p. S119).

Since ASD is primarily a social communication disorder it may be considered a social-emotional concern affecting children under five. The addition of pediatric mental health guidelines may affect the adoption of ASD-specific guidelines, but to date this has not been examined. A comprehensive list of AAP-recommended screening tools for pediatric mental health may be found in Supplemental Appendix S12 (Foy & AAP Task Force, Supplemental Appendix S12, 2010).

Recommended Screening Instruments (Birth-5)

There are a variety of standardized developmental screening instruments available for use in primary care practices with varying purposes, methods of administration (completed by parent or practitioner), estimates of sensitivity and specificity, and cost. A sensitivity and specificity of no less than 80% are recommended for developmental screening of young children (Meisels, 1989); however this depends, in part, on the purpose of the screening and the age at which it occurs. Screening tools may be designed to elicit parent concerns about a
child’s development globally, measure a range of developmental skill areas, or detect the presence of specific disorders (Drotar, Stancin, Dworkin, Sices & Wood, 2008). Practices and providers must consider the purposes of screening in their setting and the characteristics of their patient population. Screening tools also score differently across patient populations and practice settings and careful consideration must be given to the characteristics of the patient population. For instance, a practice setting serving many high-risk families may be best served by choosing a screening instrument with demonstrated sensitivity and specificity for that population. The choice of a screening instrument also depends on the experience of the providers in that practice setting and their comfort with screening tools. A review of the scientific validity of screening instruments (Drotar, Stancin, Dworkin, Sices & Wood, 2008) provides guidance for practices that are considering screening instruments for their setting.

The AAP Bright Futures publication *Coding for Pediatric Preventive Care 2011* (AAP, 2011) lists AAP-recommended developmental screening instruments, including ASD-specific instruments (Table 1.1). Assessments marked with an asterisk are also included on the AAP list of recommended mental health screening tools for pediatric primary care (Foy & AAP Task Force, Supplemental Appendix S12, 2010) and are suitable for use with children 5 and under.
Table 1.1  
\textit{AAP-Recommended Developmental Screening Instruments}

\begin{center}
\begin{tabular}{l}
*Gioia, G., Espy, K. and Isquith, P. Behavioral Rating Inventory of Executive  
    Functioning (BRIEF). Florida: Psychological Assessment Resources, Inc. 
    TN: Ellsworth and Vandemeer Press. 
*Jellinek, M. and Murphy, J.M. Pediatric Symptom Checklist: A Primary Care  
    Screening Tool to Identify Psychosocial Problems (PSC). (http://www2.massgeneral.org/allpsych/psc/psc_home.htm) 
    for Autism in Toddlers: An initial study investigating the early detection of autism  
    and pervasive developmental disorders. Journal of Autism and Developmental  
    Disorders, 31, 131-144. 
*Squires, J., Bricker, D. & Twombly, E. (2002). Ages & Stages Questionnaire-Social  
    Rating Scale
\end{tabular}
\end{center}

*Assessments marked with an asterisk are also included on the AAP list of recommended mental health screening tools for pediatric primary care

A 2010 study conducted by King et al. (2010) reported the most commonly used universal developmental screening instruments were the \textit{Parents Evaluation of Developmental Status} (PEDS; Glascoe, 1997) and the \textit{Ages and Stages Questionnaire} (ASQ-SE; Squires et al., 2002) (King et al., 2010). A more recent study across six states (Arunyanart et al., 2012) reported that the most common ASD-specific screening tool used in primary care was the \textit{Modified-Checklist for Autism in Toddlers} (MCHAT; Robins et al.,
Information about the most frequently used screening tools for pediatric mental health is not yet available.

Development of universal, ASD-specific and mental health screening guidelines has resulted in detailed protocols for early detection of developmental and behavioral disorders in early childhood and the development of a wide variety of screening instruments. However, assuring timely access to early intervention or diagnostic evaluation for young children at risk for ASD requires comprehensive study of these practices and the barriers to their implementation in primary care settings.

**Barriers to Screening**

Implementation of screening guidelines is a complex process requiring providers to evaluate the purpose(s) of screening in their practice, the characteristics of their patient population, the incidence of developmental disability in their practice, the resources and technical assistance available to implement a screening program, and the availability of assessment and intervention in their community (Drotar et al., 2008). The implementation of both universal and ASD-specific developmental screening guidelines has been challenging for primary care practitioners and, across studies and years, a number of system and knowledge barriers have been identified.

*System barriers* include time constraints (Arunyanart et al., 2012; Dosreis et al., 2006; Jarbrink & Knapp, 2001; Radecki et al., 2011; Schor, 2004; Tanner et al., 2009), limitations in reimbursement for screening visits (Golnick et al., 2009; King et al., 2005; Radecki et al., 2011; Schor, 2004), a lack of trained non-physician office staff (Radecki et al., 2011; Schor, 2004), and limited access to community resources (Schor, 2004). Individually and in
combination these system barriers have a negative influence on the implementation of screening guidelines.

*Knowledge barriers* also limit the implementation of the guidelines. Knowledge barriers include lack of familiarity with screening tools (Dosreis et al., 2006; Radecki et al., 2011; Tanner et al., 2009), lack of confidence in conducting developmental screening (Radecki et al., 2011), need for autism education (Golnick et al., 2009; Jacobsen & Mulick, 2000), fear of labeling a child too early (Happe & Frith, 1991), identification of developmental risk without adequate referral sources (Tanner et al., 2009), and difficulties with care coordination (Golnick et al., 2009; Golnick, Seal, Wey and Gaillard, 2012).

Some pediatric providers have criticized ASD-specific screening programs positing that evidence of effectiveness is scant for early ASD screening (Al-Qabandi et al., 2011; Williams & Brayne, 2006). These claims are not supported by the literature and have been refuted by the ASD research community (Dawson, Fein, Rogers, & Zwaigenbaum, 2011); however they do represent the perspectives of some pediatric providers. A closer examination of the social validity of ASD-specific screening guidelines is warranted and will inform future implementation efforts.

Finally, some providers have suggested that expectations for primary care may exceed what is feasible, and that coordination with other community resources should be considered in support of well-child care (Tanner et al, 2009; Golnick et al., 2012). Several pediatric providers, researchers and parents have proposed that well-child care be redesigned (Schor, 2004; Coker, Chung, Cowgill, Chen & Rodriguez, 2009; Tanner et al., 2009).

**Efforts to overcome barriers to screening.** The National Academy for State Health Policy partnered with the Commonwealth Fund to implement the *Assuring Better Child
Development Screening Academy (ABCD; Kay, May & Reuland, 2009). Nineteen states, the District of Columbia, and Puerto Rico participated in the ABCD Academy, which resulted in significant increases in developmental screening practices (an average of 58 percentage points) in 13 states through adoption of common policy goals, practice improvements and specific measurement approaches. Significant practice improvements included (a) office-wide systems of screening administration and (b) implementation of specific measurement approaches. Member states developed individualized approaches to measure rates of screening and identify sources of data. Fourteen of the 21 states/territories used medical records, four states used claims data, three states used parent surveys, and four states used multiple sources of data to measure the rate of developmental screening (Kay, May & Reuland, 2009).

ABCD member-state North Carolina implemented the North Carolina Assuring Better Child Health and Development project (Earls & Hay, 2006). In the year 2000 the project piloted a process for assisting pediatric offices with implementation of developmental screening to promote early identification and links to referral. The process was replicated in nine counties and statewide Medicaid policy in support of developmental screening was passed in 2004. In 2006 the project reported that more than 70% of Medicaid-eligible children in North Carolina were receiving developmental screening during well-child care (Earls & Hay, 2006).

A similar study conducted by the AAP assessed the ability of a nationally representative sample of 17 pediatric practices in 15 states to implement recommended guidelines for developmental screening (King et al., 2010). At the conclusion of the study nine of the 17 practices studied reported conducting developmental screening, but not
according to the recommended guidelines. Practices that selected parent-report screening tools and developed office-wide systems of administration and systematic data collection for screening distribution and completion were most successful at implementing the AAP guidelines (King et al., 2010).

Van Cleave et al. (2012) conducted a systematic review of the evidence for office-based interventions to increase recommended screening services in pediatric primary care. Developmental and ASD-specific screenings were among many recommended screening processes examined. Out of 2,457 articles, 23 met inclusion criteria for the systematic review process. Although findings from this study were inconclusive, the authors noted that elements of successful screening interventions utilized combinations of collaborative learning methods, office-wide system improvements, and systematic data collection (Van Cleave et al., 2012).

Successful screening initiatives include those that have implemented office improvements and measured screening practices at the state level through cross-agency and cross-sector partnerships and use of administrative claims data (Kay et al., 2009; King et al., 2010; Van Cleave et al., 2012). However, developmental screening practices are idiosyncratic and variable across states, populations and geographic regions (How et al., 2011). As economic resources dwindle it becomes critical for states to build on what has been learned in the last decade about supporting effective implementation of developmental screening in primary care (Honigfield, Chandhok, Spiegelman, 2012). Increasing access to early screening is a critical step towards accelerating early detection of ASD and providing access to early intervention.
Critical Questions

The quest to understand and improve screening for ASD and provide timely access to services has resulted in a number of critical questions that are emerging across the literature in pediatrics, in the ASD research community, and among early childhood practitioners and families. These questions reflect our collective understanding of child development and issues related to measurement within this population.

Expression of Developmental Disability in Early Childhood

A central question concerns the wide variability in expression of developmental delays and disability in young children (Dietz, Swinkels, van Dalen, van Engelend & Buitelaar, 2006; Pandey et al., 2008, Sices, 2010) and the potential for overlap and/or co-morbidity of developmental disorders during this period (Levy et al., 2010; Sheldrick & Perrin, 2010). In a narrative review of over 250 articles related to developmental surveillance and screening for children birth to age five, Marks, Glascoe and Macias (2011) reported wide variation in the progression of disorders in children prior to diagnosis of a developmental delay or disability. They raised questions about the expression of developmental delays and disabilities in early childhood.

A recent study utilized cross-sectional analyses of data from the National Survey of Children’s Health to examine services for children with four behavioral health conditions, including ASD (Sheldrick & Perrin, 2010). Findings suggest that 75 to 80 percent of children with ASD have co-morbid behavioral disorders. High rates of co-morbidity in young children at risk for ASD complicates differentiating early developmental delays from early markers of ASD or other neurodevelopmental disabilities (Yirmiya & Charman, 2010). Although researchers have begun to identify risk factors and early behavioral markers of
ASD, there continues to be uncertainty about the varied early developmental trajectories of ASD as it emerges in young children. This has critical implications for children at risk for ASD and requires further study.

**Sensitivity and Specificity of Developmental Screening Instruments**

Another set of questions concerns the ability of standardized developmental screening tools to differentiate children who have developmental delays from children at risk for ASD. The accuracy of screening instruments is measured by the psychometric properties of *sensitivity, specificity, positive predictive value and negative predictive value*. Sensitivity refers to the ability of a screening instrument to correctly detect all of the children at-risk (true positives). Screening instruments with high sensitivity are best suited for broad developmental screening programs, but may result in over-identification of children at risk and place a burden on over-taxed systems of care. Specificity refers to the ability of an instrument to correctly detect all of the children who are not at risk (true negatives). An instrument with poor specificity may result in over-identification of children who do not have ASD, with implications for families and systems of care. Adjustments to the sensitivity of an instrument will affect the specificity of that instrument, and vice versa. A sensitivity and specificity of no less than 80% are recommended for developmental screening of young children (Meisels, 1989). *Positive predictive value* (PPV) refers to the ability of a screening instrument to correctly determine the proportion of test results that are true positives. Conversely, *negative predictive value* (NPV) measures the proportion of test results that are true negatives. In the case of ASD-specific screening, PPV may be considered more important than sensitivity as providers want to ensure that a high-risk screens indicates high likelihood of the child developing ASD (Baranek, personal communication, 2012). The
purpose of the screening and the age at which it occurs will determine which psychometric properties are best considered.

**Broadband Developmental Screening Tools.** Several studies have examined the extent of broadband developmental screening tools to differentiate young children at risk for developmental delays from children at risk for ASD. The *Parents Evaluation of Developmental Status* (PEDS; Glascoe, 1997) and the *M-CHAT* (M-CHAT; Robins et al., 2001) were administered to 152 children concurrently to determine the clinical utility of the AAP-recommended guidelines (Pinto-Martin et al., 2008). Fourteen percent of the children (n=114) who passed the screening for developmental concerns on the PEDS screened positive for ASD concerns on the M-CHAT suggesting that the PEDS was not sensitive enough to detect risk of ASD (Pinto-Martin et al., 2008).

*The Infant-Toddler Checklist* (ITC; Wetherby & Prizant, 2002) a component of the *Communication and Symbolic Behavior Scales-Developmental Profile* (CSBS-DP; Wetherby & Prizant, 2002) was designed as a broadband screening instrument to detect communication delays in children ages 6-24 months. Recent findings suggest that the sensitivity of the CSBS-DP-ITC is 0.91 in children under 24 months (Oosterling et al., 2009) and it is showing promise as a screening tool for detecting young children at risk for ASD (Pierce et al. 2011). With increased interest in earlier identification of ASD, the development of ASD-specific screening instruments has become a research priority (Charwaska et al., 2007; Dietz et al., 2006; Kleinman et al., 2008; Pandey et al., 2008; Robins & Dumont-Mathieu, 2006; Watson et al., 2007).

**ASD-specific Screening Tools.** The *Modified-Checklist for Autism in Toddlers* (MCHAT; Robins et al., 2001) is a 23-item parent-report screening tool used to detect ASD
in children 16-30 months, with a PPV of 0.11 (Robins & Dumont-Mathieu, 2006). The PPV of the M-CHAT increases to 0.65 when accompanied by a follow-up interview with a caregiver (Kleinman et al., 2008). The true sensitivity and specificity of the M-CHAT are still unknown, and a high rate of false positives has been reported. To reduce the occurrence of false positives the M-CHAT should only be used with the follow-up interview (Wetherby, Brosnan-Maddox, Peace & Newton, 2008). For these reasons, researchers emphasize that providers should be cautious about making definitive statements about ASD.

The First Year Inventory (FYI; Reznick et al., 2003), while not yet available for clinical use, is the only parent-report population-based screening tool being developed to detect risk for ASD in children as young as 12 months. A retrospective pilot study exploring the face validity of the FYI reported that it successfully discriminated 12-month olds who were later diagnosed with ASD from typically developing and developmentally delayed children (Watson et al., 2007). In a recent 3-year follow up study the FYI correctly identified 77% of 12-month olds with developmental delays and disabilities. Further, 44% of the 12-month olds who initially screened positive on the FYI were diagnosed with ASD by age 3 (Turner-Brown, Baranek, Reznick, Watson & Crais, 2012). Further investigation of the FYI’s clinical utility and psychometric properties are underway, and it shows promise as an ASD-specific screening tool.

Researchers and clinicians have posed numerous practical and ethical concerns about early screening for ASD. Across studies, there is considerable variability in estimates of sensitivity and specificity of existing ASD-specific screening instruments. The psychometric properties of these tools, and optimal ages for screening are being studied extensively, existing instruments are being revised, and new ones are being developed. Further empirical
and clinical evaluation of the use of these tools for various purposes is critical, and for those using these instruments with young children, screening results must be interpreted with caution (Barton et al., 2011; Johnson & Myers, 2007; Wetherby et al., 2008; Yirmiya & Charman, 2012).

**Talking With Parents about ASD**

Providers frequently cite apprehension about raising a question of ASD in the absence of a diagnosis (Kleinman et al., 2008). Some providers prefer to engage in a period of ‘watchful waiting’ before discussing the possibility of ASD (Caronna et al., 2007; Ozonoff, 2009), while others prefer to raise concerns about ASD immediately and assist parents and caregivers in making informed decisions about intervention in the absence of an ASD diagnosis (Brian et al., 2008).

In a recent focus group study conducted at the University of North Carolina at Chapel Hill (Crais et al., 2010; unpublished raw data), parents were asked to share their views of screening for ASD at the 12-month well-child visit, particularly as the process related to concerns about their child, the kinds of information they were seeking, and how they felt about healthcare providers screening for developmental issues, including ASD. Three focus groups were held with 21 parents whose children had recently had a 12-month well child visit. Parents expressed a range of perspectives about ASD screening. Some parents were open to screening for ASD and the chance to “catch it early,” especially if there were concrete intervention steps they could take. However, if the risk of ASD was shared and parents were left without guidance, several parents stated they would prefer not to complete the screening. Other parents had questions about how definitive a screening at 12 months could be and were concerned that use of an ASD-specific screening instrument would result
in a *diagnosis* of ASD (Crais et al., 2010; unpublished raw data). Continued study of the social validity of screening practices with parents and providers is warranted.

**Alignment of Practice Guidelines**

Marks et al. (2011) point to the number of practice guidelines for detection of early developmental and behavioral problems and call for a revision of the 2006 and 2007 AAP guidelines to better align with the 2010 AAP algorithm. They re-conceptualized developmental surveillance from “longitudinal, continuous, and cumulative” (AAP, 2006, p. 407) to “*flexible*, longitudinal, continuous, and cumulative process with *multiple action steps and decision-making points*” (emphasis added; Marks et al., 2011, p. 10). Recommendations for universal surveillance and screening include (1) investigating the categories of universal screening measures (e.g., developmental, ASD and social-emotional) as well as the optimal timing and periodicity of those measures, (2) continued research on the sensitivity and specificity of universal screening measures and their ability to detect ASD, (3) prescreening with psychometrically sound instruments, (5) defining clear referral thresholds for clinicians, (6) ongoing promotion and monitoring of developmental-behavioral wellness in primary care, and (7) a post-screening process to ensure that high risk children access further evaluation and services.

Despite the questions, concerns, and ongoing dialogue associated with screening for developmental and behavioral disorders in early childhood much progress has been made in the last decade. Strong evidence suggests that young children at risk for ASD have experienced improved access to early intervention and early diagnosis when standardized developmental screening is completed during well-child care.
Summary

Previous research suggests that early behavioral markers of ASD may appear between 9 and 12 months of age (Baranek, 1999; Brian et al., 2008; Bryson et al., 2007; Colgan et al., 2006; Landa et al., 2007; Maestro et al., 2005; Osterling & Dawson, 1994; Osterling et al., 2002; Ozonoff et al., 2008; Ozonoff et al., 2010; Zwaigenbaum, 2005) and that early and intensive behavioral intervention significantly improves developmental outcomes for children with ASD (Dawson et al., 2010; Kasari et al., 2006; McGee et al., 1999; Reichow, 2011; Warren et al., 2011; Woods & Wetherby, 2003). Yet, the period between recognition of concern and referral for early intervention or diagnostic evaluation can be as long as four years with a mean age of diagnosis between 5 and 6 years of age (Mandell et al., 2010; Shattuck, 2009). Racial and ethnic disparities may result in even later diagnoses (Fountain et al., 2010; Shattuck et al., 2009; Mandell et al., 2009, Rosenberg et al., 2011). Children with ASD often have co-morbid developmental delays, which early screening may detect well before a diagnosis of ASD is made (Bethell et al., 2011); therefore, universal screening during well-child care is critical for young children at risk for ASD. States that have been successful at implementing and sustaining developmental screening initiatives have examined and measured screening practices through cross-agency partnerships and use of administrative claims data (Kay et al., 2009); however, continued efforts to understand access to screening in specific regions of the country are warranted. To provide context for understanding the methods and results of the current study, key demographic information and other characteristics of the state of New Hampshire will be described.
New Hampshire

Demographics

New Hampshire is a small New England state (8,953 square miles) with an estimated population of just over 1 million people. Twenty-one percent of the population (~210,000) is aged birth to 18 and five percent of the population (~50,000) is aged birth to five years (US Census Bureau, 2011). The state is divided into ten counties with nearly 77% of New Hampshire’s population concentrated in five southern counties (Hillsborough, Rockingham, Merrimack, Strafford and Belknap). For the purposes of this study a distinction was made between rural counties with a population less than 100,000 and urban counties with a population greater than 100,000 (Figure 1.1).

Between 2006 and 2010 the median household income in New Hampshire was $63,277 and approximately 8% of the population lived below the poverty line. Ninety-one percent of individuals over age 25 were high school graduates and 31% completed a Bachelor’s Degree. The state is largely white and non-Hispanic. Eight percent of persons over age five speak a language other than English in the home. More detailed information about racial and ethnic representation in New Hampshire is provided in Table 1.1.
Figure 1.1

*New Hampshire Population by County*

Table 1.2

New Hampshire Demographics

<table>
<thead>
<tr>
<th>Race</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>93.9</td>
</tr>
<tr>
<td>Black</td>
<td>1.1</td>
</tr>
<tr>
<td>American Indian and Alaska Native</td>
<td>0.2</td>
</tr>
<tr>
<td>Asian</td>
<td>2.2</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islanders</td>
<td>0.0</td>
</tr>
<tr>
<td>Two or more races reported</td>
<td>1.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic or Latin origin</td>
<td>2.8</td>
</tr>
</tbody>
</table>

Distribution of Health Care Providers

The Dartmouth Institute for Health Policy and Clinical Practice studied the distribution of pediatricians and family practice physicians caring for children in the state and nation (Shipman, Lan, Chang & Goodman, 2011). Their findings suggest that New Hampshire has primary care service areas where there are no providers caring for children, or where provider caseloads exceed 3,000 children per physician. An estimated 16.6% or 51,150 children live in low-supply areas, which are also largely poor and rural (Shipman et al., 2011).

New Hampshire Early Intervention System

New Hampshire’s Family Centered Early Supports and Services Program (NH FCESS) serves children birth to three years and is administered by the NH Department of
Health and Human Services, Bureau of Developmental Services through 10 county-level area agencies. In 2010 NH FCESS received 1918 referrals, over half of which (52%) were made by health care providers. Eligibility categories in NH include: (1) a diagnosed established condition resulting in developmental delay, (2) atypical development documented by family and qualified personnel (e.g., self-injurious, sleep disturbances, chronic anxiety, aggression), (3) delays of 33% in one or more area of development as determined by multidisciplinary evaluation, and (4) child or family experiences more than 5 risk factors for substantial delay (e.g., birth weight, history of abuse or neglect, prenatal drug exposure, nutritional problems, family history of developmental disability) (NH Department of Health and Human Services, 2011).

**Developmental Screening in New Hampshire**

In New Hampshire, a state with an estimated 66,000 children ages birth to five years (US Census Bureau, 2010), the Commonwealth Fund State Scorecard reported only 18.1% of children received a developmental screening in 2007, ranking NH 32nd in the nation on this indicator (How et al., 2011). Similarly, data from the 2009-2010 National Survey of Children with Special Health Care Needs reported that 69% of parents had not received a developmental screening within the last year during their child’s well child visit (Data Resource Center for Child and Adolescent Health, 2011).

In 2009, the New Hampshire Department of Health and Human Services, Division for Children, Youth, and Families invested in a pilot program called Watch Me Grow, a developmental screening and referral initiative aimed at developing a network of screening providers in the state. As of this writing Watch Me Grow has been successfully implemented in 12 locations across the state and a total of 690 screenings have been conducted (D.J.)
Nelson, personal communication, 2012). Through *Watch Me Grow* New Hampshire’s Family Resource Centers train local providers from multiple disciplines to work with parents to complete the *Ages & Stages Questionnaire-3* (ASQ; Squires et al., 2002) in a variety of settings. Efforts to track screenings and monitor referrals in the state are currently underway, but clearly New Hampshire has invested in creating mechanisms intended to increase access to early screening and diagnosis.

**New Hampshire Autism Registry**

New Hampshire has also invested in documenting new cases of ASD in the state. In November 2008, the New Hampshire Department of Health and Human Services implemented the first state autism registry in the country for the purpose of recording ASD diagnoses. Health care providers who are qualified to make a diagnosis of autism spectrum disorder are required to report new cases of ASD in New Hampshire to the NH Department of Health and Human Services. A total of 450 ASD diagnoses were reported in New Hampshire by 51 unique providers between January 2009 and December 2011 (E. Collins, personal communication, July 26, 2012). To date, efforts to measure compliance with this reporting requirement have not been implemented and the data must be interpreted with caution. Table 1.2 provides specific information regarding the ages of the children reported to the registry in each year.
New Hampshire’s developmental screening initiative and autism registry are important first steps towards improving the rate of developmental screening in the state and documenting new cases of ASD. One strategy employed in monitoring successful screening initiatives has been measurement of screening practices through use of administrative claims data (Kay et al., 2009). The present study built upon this strategy.

**Purpose and Significance of the Current Study**

The present study was designed to understand the relationship between the use of standardized developmental screening instruments in primary care and timing of ASD diagnosis by examining administrative claims data for young children who later received a diagnosis of ASD in New Hampshire. Findings that clearly link earlier diagnosis to the utilization of developmental screening instruments may serve to increase adherence to screening guidelines in a profession that is guided by evidence-based practices. Specifically, the study addressed the following research questions:
1. Are there significant differences in the mean age of ASD diagnosis for those children screened and those not screened for developmental issues during well-child visits?

*Hypothesis:* The initial hypothesis was that children who received developmental screening during well-child care would be diagnosed earlier than those who were not screened.

2. Are there significant differences in mean age of ASD diagnosis for children who were screened at one time point and children who were screened at more than one time point for developmental issues during well-child visits?

*Hypothesis:* The initial hypothesis was that children who received developmental screening at more than one time point would be diagnosed earlier than those who were screened once.

3. What is the relative strength of the association between gender, geographic region or provider type and age at diagnosis of ASD?

*Hypothesis:* The initial hypothesis was that Gender would be the strongest predictor on age of ASD diagnosis, followed by Geographic Region and Provider Type when controlling for other variables in the analysis.
CHAPTER 2

Method

The current study was designed to examine developmental screening practices in the state of New Hampshire using administrative claims data for young children who later received a diagnosis of ASD. The purpose was to understand the relationship between the use of screening practices and a number of factors including the age of diagnosis of ASD.

Data Source

The New Hampshire Comprehensive Health Care Information System (NH-CHIS) was created in 2005 as a result of a NH State statute to make health care data available to “insurers, employers, providers, purchasers of health care, and state agencies to continuously review health care utilization, expenditures, and performance in New Hampshire…” (Chapter 420-G: Portability, Availability, Renewability of Health Care Coverage, 2005). The New Hampshire Insurance Department (NHID) and the NH Department of Health and Human Services (NH-DHHS) partner to administer the NH-CHIS. Health insurance carriers submit encrypted medical, dental and pharmacy claims and eligibility files from public and private payers to the state at regular intervals. NH-CHIS contains a subset of New Hampshire Commercial Claims, including those from the following health insurance carriers: Anthem, Cigna and Harvard Pilgrim and a subset of New Hampshire Medicaid Claims data. The system provides unprecedented access to comprehensive health care claims data collected in primary care settings and provides important information on cost, quality, utilization and barriers to care (Love, Custer & Miller, 2010; Miller, Love, Sullivan, Porter &
Costello, 2010). The data currently reside at the NH-DHHS Office of Medicaid Business and Policy in Concord, NH; however, the University of New Hampshire’s Institute on Health Policy and Practice (NHIHPP) has permission to use a limited use data file for research purposes and New Hampshire is one of the first states in the nation to make this type of data available to researchers. The current investigation required a NH-DHHS approved limited-use application to access the data, as well as approval by the NH-DHHS and the Institutional Review Boards of the University of North Carolina at Chapel Hill and the University of New Hampshire.

The NH-CHIS data are robust from 2005 to the present and medical, pharmacy and dental claims are entered into the NH-CHIS system at 6-month intervals. A study start date of January 2007 was determined in order to capture the publishing of the American Academy of Pediatrics ASD Screening Guidelines in October 2007. The end date for this study was determined by the limited-use application, which was submitted in June 2011 and captured data through December 2010 resulting in a 48-month study period between January 1, 2007 and December 30, 2010.

**Sample.** The following algorithm was utilized to extract the sample of children across the commercial and Medicaid data sets. First, all individuals with ICD-9 diagnostic codes of 2990 Infantile Autism, 29900 Infantile Autism-Active, or 29901 Infantile Autism-Residual (Diagnostic and Statistical Manual of Mental Disorders-IV-TR, American Psychiatric Association, 2000) were extracted from a subset of New Hampshire Commercial Claims, including those from Anthem, Cigna and Harvard Pilgrim resulting in a subset of 1553 children with a primary or secondary diagnosis of ASD. Children with birthdates in the 48-month period between January 1, 2007 and December 30, 2010 were extracted from the
Commercial Claims resulting in 85 unique members (81% M, 19% F) with a primary or secondary diagnosis of ASD. The same algorithm was applied to the New Hampshire Medicaid Claims data resulting in 1657 individuals with a primary or secondary diagnosis of ASD and 124 unique members (72% M, 28% F) with birthdates in the 48-month period between January 1, 2007 and December 30, 2010.

All de-identified medical, dental and pharmacy claims and eligibility files associated with each unique member were included in the Commercial (n=85; 9,709 claims) and Medicaid (n=124; 25,248 claims) subsets of data. For the purposes of this study, only medical claims and eligibility files containing variables of interest were accessed and a subset of data was created containing only these variables (Appendix A).

Exclusion Criteria. For those children with gaps in insurance coverage the following exclusion criterion was established. First, those children with less than 6 months of continuous insurance coverage were excluded. Two children from the Medicaid sample and five children from the Commercial sample were removed. Second, the child’s birth year and month were examined relative to the 48-month study period January 2007 through December 2010. For example, a child with a birth date of January 2007 would have been one month old in Study Month #2 (February 2007). Next, the child’s age in months was examined relative to the gap in insurance coverage. If a gap in coverage occurred in a month when a periodic developmental screening might have taken place (9, 18, 24 or 30 months) that child was excluded from the study. If the gap in insurance coverage appeared one month before or after a periodic screening might have taken place, then the child was also excluded. A total of 17 additional children (9 Medicaid, 8 Commercial) were excluded using these criteria. To confirm the legitimacy of the diagnostic code for ASD, the code must have
appeared at least once in conjunction with a diagnostic office visit to be included in the final sample. Twelve children were excluded from the Commercial sample and 29 children in the Medicaid data were excluded from the final sample based on these criteria. The final sample is described in Table 2.1.

**Increasing power.** To increase statistical power the Medicaid and Commercial data were merged for all analyses. The feasibility of merging the subsets of data was examined through a Fisher’s Exact Test. There were no significant differences between the proportion of children screened and not screened in the Medicaid and Commercial populations ($p = 0.67$; two-tailed) and the variables were identical across the two NH-CHIS data sets. However, demographic and socioeconomic differences do exist between these two insured populations and results will require clear and cautious interpretation. The final merged sample included 144 children with a diagnosis of ASD (60 Commercial, 84 Medicaid).

**Participant Characteristics**

Table 2.1

<table>
<thead>
<tr>
<th>Comparison Demographics for Medicaid and Commercial Samples n (%)</th>
<th>Medicaid (n=84)</th>
<th>Commercial (n=60)</th>
<th>Combined (n=144)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>70 (83%)</td>
<td>51 (85%)</td>
<td>121 (84%)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (17%)</td>
<td>9 (15%)</td>
<td>23 (16%)</td>
</tr>
<tr>
<td><strong>Geographic Region</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>65 (77%)</td>
<td>45 (75%)</td>
<td>110 (76%)</td>
</tr>
<tr>
<td>Rural</td>
<td>14 (17%)</td>
<td>5 (8%)</td>
<td>19 (15%)</td>
</tr>
<tr>
<td>Non-NH*</td>
<td>5 (6%)</td>
<td>10 (17%)</td>
<td>15 (10%)</td>
</tr>
</tbody>
</table>
**Geographic Region.** The sample was further divided based on the geographic region in which the child resided. New Hampshire has ten counties including 5 rural counties that account for less than 23% of the total population and 5 urban counties that account for the remaining 77%. For the purposes of this study, this rural/urban distinction was defined such that rural counties were those with a population of less than 100,000 and urban counties were those with a population greater than 100,000.

**Provider Type.** Thirteen provider types appeared in conjunction with diagnostic office visits in the original data. Provider types were collapsed into 7 categories for the regression analyses based on the nature of the services. For instance, mental health related services (psychiatry, psychology, behavioral health) and general medicine (Family Practice, Internal Medicine and Physical Medicine) were grouped together. Pediatric medicine, neurology, and Advanced Registered Nurse Practitioner were isolated as unique categories (Table 2.2).

Table 2.2

*Diagnostic Provider Type  (n=143)*

<table>
<thead>
<tr>
<th>Provider Type</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric Medicine</td>
<td>37</td>
<td>(25.87)</td>
</tr>
<tr>
<td>Family Practice/General Practice/Internal Medicine/Physical Medicine</td>
<td>23</td>
<td>(16.08)</td>
</tr>
<tr>
<td>Psychiatry/Psychology/Behavioral Health/Social Service</td>
<td>18</td>
<td>(12.58)</td>
</tr>
<tr>
<td>Neurology</td>
<td>27</td>
<td>(18.88)</td>
</tr>
<tr>
<td>Advanced Registered/Nurse Practitioner</td>
<td>11</td>
<td>(7.69 )</td>
</tr>
<tr>
<td>Other Professional/Ancillary Provider Laboratory</td>
<td>12</td>
<td>(8.39)</td>
</tr>
<tr>
<td>Acute Care Facility Provider/Ambulatory Health</td>
<td>15</td>
<td>(10.48)</td>
</tr>
</tbody>
</table>
**Diagnostic codes.** Timing of first ASD diagnosis for each child in the study was determined by examining the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM; 2011) diagnostic codes appearing in the data. All individuals with ICD-9 diagnostic codes of 2990 Infantile Autism, 29900 Infantile Autism-Active, or 29901 Infantile Autism-Residual (Diagnostic and Statistical Manual of Mental Disorders-IV-TR American Psychiatric Association, 2000) were included this study. The diagnostic code for ASD must have appeared at least once in conjunction with a diagnostic office visit to be included in the final sample.

**Procedural codes.** The following *Current Procedural Terminology* (CPT; American Medical Association, 2011) standardized codes were identified to determine when developmental screening instruments were utilized. The existence, timing, and frequency of CPT codes for developmental screening were examined for each child in the analysis in relation to the timing of the first ASD diagnostic code appearing in the data for that child. The procedural codes for developmental screening used in this study are listed in Table 2.3.

Table 2.3

*Current Procedural Terminology (CPT) Codes*

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>96110</td>
<td>Developmental screening, with interpretation and report, per standardized instrument form</td>
</tr>
<tr>
<td>96111</td>
<td>Developmental testing, (includes assessment of motor, language, social, adaptive, and/or cognitive functioning by standardized developmental instruments) with interpretation and report</td>
</tr>
</tbody>
</table>
CPT codes and Healthcare Common Procedure Coding System (HCPCS; Center for Medicare and Medicaid Services, 2012) were utilized to determine the type of office visit occurring in conjunction with the first use of the ICD-9 diagnostic code for ASD (Table 2.4).

Table 2.4

<table>
<thead>
<tr>
<th>Healthcare Common Procedure Coding System (HCPCS) Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1024</td>
</tr>
<tr>
<td>S0302</td>
</tr>
</tbody>
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<tr>
<th></th>
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<tbody>
<tr>
<td>99214</td>
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</tbody>
</table>

**Screening Setting.** Setting was examined as a potential variable influencing access or timing of screening. While each occurrence of the developmental screening CPT code 96110 was coded as an office visit (11), no other information on setting was available in the data. As a result, only the distinction between office visit and non-office visit could be made.

**Race and ethnicity.** Data on race were unavailable in both subsets of Commercial and Medicaid claims. Ethnicity data were included in the Medicaid claims, but poorly coded and difficult to utilize (874,000 of 883,000 member records as unknown in one given month) in the Commercial file. Therefore the race and ethnicity variables were removed from the
Medicaid data. Given the homogeneity of New Hampshire’s population (White 93.9%, non-Hispanic 92.3%) it is unclear how much this variable would contribute to the model. For complete information on race and ethnicity estimates for New Hampshire see Table 1.1 (United States Census Bureau, 2010).

Data Analysis Procedures

All of the analyses were conducted using SAS v. 9.3 (Cary, NC).

Descriptive statistics. The data were screened to examine all univariate statistics. Descriptive statistics for age at diagnosis were calculated, plotted and examined for assumptions of normality for children who (a) received developmental screening and children who did not and (b) received screening at one time point and those that were screened at more than one time point, as well as (c) for each variable in the regression analysis (gender, geographic region, and provider type). Further, age of diagnosis comparisons were made by gender, geographic region and provider type.

Research question 1. The first research question addressed differences in age of diagnosis when a child did and did not have a screening. Specifically, the research question asked: Are there significant differences in the mean age of ASD diagnosis for those children screened and those not screened during well-child visits?

Given that the assumption of equal variances was met, an independent groups t-test was performed to compare the mean age at diagnosis of ASD for those children screened and those children not screened during well-child care, using the PROC TTEST procedure in SAS. The procedure required an examination of the means of the two groups, which produced a t-value. Statistically significant findings would suggest that the use of standardized developmental screening tools in well-child care leads to earlier diagnoses of
ASD. A Cohen’s d formula was then used to calculate effect sizes and determine the magnitude of the difference in age of diagnosis when a standardized developmental screening tool was and was not completed. The formula for the $d$ was:

$$d = \frac{\mu^1 - \mu^2}{\sigma}$$

where $\mu^1$ = the mean age at diagnosis for children who were screened, $\mu^2$ = the mean age at diagnosis for children who were not screened, and $\sigma$ = the pooled standard deviation.

**Research question 2.** The second research question further investigated the impact of screening by examining the relationship between the number of screenings that were completed and age of diagnosis. The specific research question was: Is there a significant difference in the mean age of ASD diagnosis for children who were screened at one time point and children who were screened at more than one time point during well-child care?

After determining that the variances across the two groups were equal, an independent groups t-test was performed to compare the mean age at diagnosis of ASD for children screened one time and those children screened more than one time during well-child care, using the PROC TTEST procedure in SAS. Again, if the t-value resulted in a p-value of less than 0.05 ($t_{df} = X$, $p > .05$), the results were considered statistically significant suggesting that the use of standardized developmental screening tools more often in well-child care leads to earlier diagnoses of ASD. The magnitude of the difference was investigated using a Cohen’s $d$ effect size calculation.

**Research question 3.** The third research question looked at the relationship among a number of variables related to age of diagnosis of ASD. The specific question asked: What is the relative strength of the association between gender, geographic region or provider type and age at diagnosis of ASD? To answer the question completely, several follow-up
questions were required. These follow-up questions were: Given provider type and geographic region, what does gender contribute? Given gender and provider type, what does geographic region contribute? Given geographic region and gender, what does provider type contribute?

A series of seven multiple linear regression analyses were conducted to examine the association between gender ($X_1$), geographic region ($X_2$), and provider type ($X_3$) on age at diagnosis of ASD ($Y$), using the PROC GLM (regression analysis) procedure in SAS. Gender and Geographic Region were given binary dummy codes (0,1) in the final analytic file. The seven categories of Provider Type were coded 0 through 6. Three linear regressions were run on each predictor variable (gender, geographic region, provider type) to determine the influence of each on age of diagnosis; all possible permutations were run and interactions explored. Finally, all variables were entered into the model. If the summary F-value resulted in a p-value of less than 0.05, the results were considered statistically significant. $R^2$ values were used to report the variation attributable to each parameter in the final model and interaction effects were analyzed. A t-value was estimated for each parameter, and its corresponding p-value was used to determine statistical significance.
CHAPTER 3

Results

This study examined developmental screening practices for young children with ASD in the state of New Hampshire. The purpose was to understand the relationship between the use of screening practices and a number of factors including the age of diagnosis of ASD. Data were extracted from the New Hampshire Comprehensive Health Care Information System (NH-CHIS) with a final data set including 144 children born between January 1, 2007 and December 30, 2010.

Descriptive Statistics

As noted previously, of the 144 participants in this study, 121 (84%) were male and 23(16%) were female (Table 2.1). The mean age of diagnosis for children in the sample was 28.97 months ($\sigma^2 = 51.07; \sigma = 7.146$) and the range in age of diagnosis was 9-46 months. Mean age of diagnosis for girls was slightly lower ($\mu = 27.77, \sigma = 6.45$) than for boys ($\mu = 29.34, \sigma = 7.21$). Figure 3.1 describes gender distribution by geographic region.
Pediatricians and neurologists conducted the highest frequency of diagnostic office visits in the southern region of the state, followed by the Family Practice/Internal Medicine group and then by Psychiatry/Psychology. In the northern region, Pediatricians were most likely to diagnose ASD, followed by Acute Care Physicians, Advanced Registered Nurse Practitioners, and then by Family Practice/Internal Medicine group (Table 3.1).
Table 3.1

<table>
<thead>
<tr>
<th></th>
<th>Urban n=109</th>
<th>Rural n=19</th>
<th>Unknown n=16</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric</td>
<td>26 (23.85)</td>
<td>7 (36.84)</td>
<td>4 (25.00)</td>
</tr>
<tr>
<td>Gen Med</td>
<td>17 (15.59)</td>
<td>2 (10.52)</td>
<td>4 (25.00)</td>
</tr>
<tr>
<td>Beh Med</td>
<td>17 (15.59)</td>
<td>1 (5.26)</td>
<td>1 (6.25)</td>
</tr>
<tr>
<td>Neuro</td>
<td>25 (22.93)</td>
<td>1 (5.26)</td>
<td>1 (6.25)</td>
</tr>
<tr>
<td>ARNP</td>
<td>7 (6.42)</td>
<td>3 (15.78)</td>
<td>1 (6.25)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (8.25)</td>
<td>1 (5.26)</td>
<td>2 (12.50)</td>
</tr>
<tr>
<td>Acute</td>
<td>8 (7.33)</td>
<td>4 (21.05)</td>
<td>3 (18.75)</td>
</tr>
</tbody>
</table>

Twenty-eight children (19%) had CPT code 96110 in their administrative claims file, indicating a developmental screening during well child care. Twenty children (71%) received screening in the southern region of the state, 2 (7%) children received screening in the northern region, and 6 (21%) children received screening in unreported regions. Of the 28 children who received a screening, 16 (57%) received developmental screening at one time point and 12 (42%) received screening at more than one time point. Results are reported below relative to the research questions guiding the overall investigation.

**Question 1: Children screened and not screened during well-child visits**

The initial hypothesis was that children who received developmental screening during well-child care would be diagnosed earlier than those who were not screened. An independent groups t-test was used to test for statistically significant differences in mean age.
of ASD diagnosis for children who received a standardized developmental screening during well-child care (n= 28) and those who did not receive a screening (n= 116). The test of Equality of Variances was met and the t-test was performed using the PROC TTEST procedure in SAS. The data suggested no significant differences in mean age of ASD diagnosis ($t_{142} = 1.88, p = 0.0968$, one-tailed, $d=0.3988$) for children who received a standardized developmental screening during well-child care ($\mu=26.71$, $\sigma=6.92$) and those who did not ($\mu=29.51$, $\sigma=7.12$).

**Question 2: Children screened at one time point and more than one time point during well-child visits**

The second hypothesis was that children who received developmental screening at more than one time point would be diagnosed earlier than those who were screened once. An independent groups t-test was used to test for statistically significant differences in mean age of ASD diagnosis between children who received a standardized developmental screening at one time point (n= 16) and those who received a screening at more than one time point (n= 12). The test of Equality of Variances was met ($p > 0.0565$) and the t-test was performed using the PROC TTEST procedure in SAS. The data showed a statistically significant difference ($t_{24.164} = -1.80, p = 0.0415$, one-tailed) in mean age of ASD diagnosis for those children who received a screening at one time point ($\mu=24.75$, $\sigma=7.92$) and those who were screened at more than one time point ($\mu=29.33$, $\sigma=4.35$). A Cohen’s $d$ effect size calculation was completed indicating a moderate effect size ($d=-0.7168; r = -0.337$); however, the direction of the effect was opposite from the stated hypothesis. Children who were screened at more than one time point were diagnosed later than children screened once.
Since this was not part of the stated hypothesis the analysis did not pick up differences at the other end of the distribution.

**Question 3: What is the relative strength of the association between gender, geographic region or provider type and age at diagnosis of ASD?**

The third hypothesis was that Gender, Geographic Region, and Provider Type would each make unique contributions to timing of ASD diagnoses. Three linear regressions were run on each predictor variable (Gender, Geographic Region, Provider type) to examine the extent to which each variable explained individual differences in age of diagnosis using the PROC GLM (general linear model) procedure in SAS (Table 3.2). Neither Gender (Model 1) nor Provider Type (Model 3) were independent predictors of age of diagnosis (NS). However, Geographic region (Model 2) was statistically significant $F(1, 126) = 4.00, p = 0.04$ and accounted for approximately 31% of the variance in age of diagnosis. Unexpectedly, mean age of diagnosis was lower in rural regions ($\mu=27.05, \sigma=5.62$) than urban regions of the state ($\mu=29.70, \sigma=7.42$).
Table 3.2

*Predicting Age of ASD Diagnosis: Univariate Models*

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>$R^2$</th>
<th>df</th>
<th>F</th>
<th>t-value</th>
<th>p-level</th>
</tr>
</thead>
<tbody>
<tr>
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<td>1</td>
<td>1.06</td>
<td>-1.03</td>
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<tr>
<td>Model 2</td>
<td>Geographic region</td>
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<td>4.00</td>
<td>2.00</td>
<td>0.047*</td>
</tr>
<tr>
<td>Model 3</td>
<td>Provider Type</td>
<td>0.019</td>
<td>6</td>
<td>0.45</td>
<td></td>
<td>0.841</td>
</tr>
<tr>
<td></td>
<td>Pediatric Medicine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FP/GP/IntMed/PhysMed</td>
<td></td>
<td></td>
<td></td>
<td>1.51</td>
<td>0.134</td>
</tr>
<tr>
<td></td>
<td>Pyschi/Psychol/BehavHealth</td>
<td></td>
<td></td>
<td></td>
<td>1.04</td>
<td>0.298</td>
</tr>
<tr>
<td></td>
<td>Neurology</td>
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<td></td>
<td></td>
<td>1.25</td>
<td>0.211</td>
</tr>
<tr>
<td></td>
<td>ARNP</td>
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<td></td>
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<td>1.31</td>
<td>0.193</td>
</tr>
<tr>
<td></td>
<td>Other/Ancillary</td>
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<tr>
<td></td>
<td>Acute Care/Amb Care</td>
<td></td>
<td></td>
<td></td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

* $p < 0.05$

A series of 3 linear regressions were performed on all possible permutations to examine co-variance among variables (Table 3.3). For each set of permutations interaction effects were examined. When controlling for Gender (Model 4) and Provider Type (Model 5), Geographic Region was no longer predictive of age of diagnosis ($p = 0.058; p = 0.052$ respectively).
Table 3.3

*Predicting Age of ASD Diagnosis: Bivariate Models*

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<tr>
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<th>R²</th>
<th>df</th>
<th>F</th>
<th>t-value</th>
<th>p-level</th>
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</thead>
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<td>3.64</td>
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<td>Gender X GeoRegion</td>
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<td>1</td>
<td>0.04</td>
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<td>0.833</td>
</tr>
<tr>
<td>Model 5</td>
<td>0.084</td>
<td>13</td>
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<td>0.652</td>
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<td>0.670</td>
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<td></td>
<td>-0.00</td>
<td>1.00</td>
</tr>
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<td>Pyschi/Psychol/BehavHea</td>
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<td>0.06</td>
<td>0.951</td>
</tr>
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<td>-0.55</td>
<td>0.580</td>
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<td>ARNP</td>
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<td>-0.21</td>
<td>0.833</td>
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<td>0.43</td>
<td>0.667</td>
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</tr>
<tr>
<td>GeoRegion X Provider</td>
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<td></td>
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<tr>
<td>Model 6</td>
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<tr>
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<td>0.639</td>
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<td></td>
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<tr>
<td>Gender X Provider</td>
<td>1.68</td>
<td></td>
<td></td>
<td>0.132</td>
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</tr>
</tbody>
</table>

*p < 0.05*
Given geographic region and gender, what does provider type contribute? Given provider type and geographic region, what does gender contribute? Given gender and provider type, what does geographic region contribute?

To address these remaining research questions each variable was entered into the model to examine the influence of all three predictor variables on age of diagnosis. After controlling for all variables in the analysis (Model 7), Geographic region was no longer significant $F(8, 127) = 1.27, p = 0.059$. Although Provider type was not statistically significant overall ($p=0.653$), Pediatric Medicine was approaching significance ($p=0.054$).

Table 3.4

<table>
<thead>
<tr>
<th>Predicting Age of ASD Diagnosis: Full Model</th>
<th>$R^2$</th>
<th>df</th>
<th>F</th>
<th>t-value</th>
<th>p-level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 7</td>
<td>0.07</td>
<td>8</td>
<td>1.27</td>
<td>0.264</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>2.39</td>
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<td>0.124</td>
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</tr>
<tr>
<td>Geographic Region</td>
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<tr>
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</table>

*p < 0.05
CHAPTER 4

Discussion

Young children at risk for ASD are likely to experience early delays in one or more domains of development. Pediatric primary care providers, who see young children at regular intervals from birth to three years of age, are well positioned to identify these early risk factors. Better coordination between early childhood professionals and primary care providers will ensure that children with ASD risk factors have timely access to early and behavioral intervention. Previous research has demonstrated that young children are three times more likely to receive early intervention if a standardized developmental screening tool was completed during well-child care (Bethell et al., 2011).

Universal developmental screening completed during well-child care accelerates the path to intervention by detecting delays in development well before a diagnosis of ASD can be made. Therefore, the use of universal developmental screening instruments during well-child care is critical for young children at risk for ASD. Yet, prior studies suggest that only 50%-75% of pediatric primary care providers utilize standardized developmental screening instruments (Arunyanart et al., 2012; Sand et al., 2005; Sices et al., 2004).

The current study examined the frequency of standardized developmental screening during well-child care on timing of ASD diagnoses in the state of New Hampshire through health care administrative claims data. Further, the associations between gender, geographic region and provider type on mean age of ASD diagnosis were investigated.
Rates of Developmental Screening in New Hampshire

Previous research reported New Hampshire’s rate of standardized developmental screening at 18% (How et al., 2011). In this study, 19% of the children later diagnosed with ASD received a standardized developmental screen. These findings are consistent with previous research and suggest relatively low utilization of standardized screening instruments in the state. The high percentage of the study sample living in the southern region of the state, which is considered a high-supply physician area (Shipman, et al. 2011), highlights the low utilization of screening instruments in the state. Study of screening utilization rates and barriers to developmental screening in New Hampshire may be worthy of further investigation.

Influence of Developmental Screening on Age of Diagnosis

The hypothesis that children who were screened with a standardized developmental screening instrument during well-child care would be diagnosed earlier than those who were not screened was not supported by this study. There were no statistically significant differences in mean age of ASD diagnosis for children who received a standardized developmental screening during well-child care and those who did not receive a screening.

There are several potential explanations for these findings. First, only 28 (19%) of the 144 children in the study had CPT code 96110 in their claims file, reducing the sample size and subsequent power of the study. The results of this analysis were approaching significance (p=0.0968) and future studies with a larger sample are warranted. Second, the steps in the referral process are multifaceted and involve intra-office communication, communication across disciplines, systems and agencies. In a recent pilot study conducted by the AAP (King et al., 2010) monthly referral rates following an at-risk screening averaged
only 61% over the 9-month study period and approaches to referral varied widely. Some clinics referred children with a failed screen for diagnostic assessment, some referred for private therapy, while still others referred to public early intervention programs, depending on the nature and severity of the developmental concern. Investigating referral practices was beyond the scope of the study. However, further study of referral practices following an ‘at-risk’ screening in both primary care and the early childhood community is warranted and may affect the timing of ASD diagnosis in young children. Further, examining differences in access to early intervention services between children who were screened and not screened has implications for future study.

**Frequency of Developmental Screening and Influence on Age of Diagnosis**

The hypothesis that children who received developmental screening at more than one time point would be diagnosed earlier than those who were screened at one time point was not supported by the data. The study found statistically significant differences in mean age of ASD diagnosis for children who received a screening at one time point ($\mu=24.75$, $\sigma=7.92$) and those who received screening at more than one time point ($\mu=29.33$, $\sigma=4.35$); however, the direction of the effect was opposite from the stated hypothesis with mean age of ASD diagnosis slightly *later* for those children who were screened at more than one time point. Since this was not part of the stated hypothesis the analysis did not pick up differences at the other end of the distribution.

These findings were unexpected, but upon reflection they are logical. In this study, children who were screened at more than one time point experienced later diagnoses, suggesting that providers may have engaged in a period of ‘watchful waiting’ between screenings before referring for diagnostic evaluation after a second screen. These children
may have presented a developmental profile with milder developmental delays or unclear early markers of ASD, which resulted in later diagnoses. Previous studies report that 75-80% of children with ASD experience co-morbid developmental delays (Sheldrick & Perrin, 2012), and parents often express concern within the first year (DeGiacomo & Fombonne, 1997; Ozonoff, 2009). However, discussions in the literature recommend providers engage in periods of ‘watchful waiting’ when concerns arise (Caronna et al., 2007; Ozonoff et al., 2009) before moving to diagnosis. Due to the nature of administrative claims data, the specific results of developmental screenings were unavailable in the current study. A methodology examining the results of developmental screening could indicate the nature of first concern during well child care and provide information about the practice of ‘watchful waiting’. Further examination of developmental screening profiles resulting in referral for early intervention services may inform future practice. In addition, the point of referral is a critical intersection of service sectors (pediatric primary care and early intervention) requiring further examination. There is strong potential for reciprocity between early childhood professionals, who have comprehensive knowledge of child development, and the pediatric primary care community that could strengthen the referral process.

**Influence of Gender, Geographic Region and Provider Type on Age of Diagnosis**

The regression analyses tested the extent to which each predictor variable (Gender, Geographic Region and Provider Type) explained individual differences in age of diagnosis of ASD.

**Gender.** Prior research indicates that males are diagnosed at earlier ages than females (Rosenberg et al. 2011; Mandell et al., 2005; Shattuck et al., 2009). The current study hypothesized that gender would be the strongest predictor of age at diagnosis. This
hypothesis was not supported by the data, and may have been affected by the small sample of females (23) in the study. Although these findings were not statistically significant, the mean age of diagnosis for girls in the study was slightly lower (\(\mu=27.77, \sigma=6.45\)) than for boys (\(\mu=29.34, \sigma=7.21\)).

**Geographic Region.** The current study hypothesized that mean age of diagnosis would be later for children in rural regions of New Hampshire than those in urban regions. However, the data did not support this hypothesis. Geographic region made an *independent* contribution to age of diagnosis, accounting for 31% of the variance when compared to the null model. When controlling for other variables (gender and provider type), geographic region no longer made a unique contribution to the model.

Providers in the northern (more rural) regions of New Hampshire diagnosed ASD slightly earlier than providers in southern (more urban) regions of the state. While not statistically significant, this was an unexpected finding given the distribution of health care providers in the state. As discussed earlier, northern New Hampshire has primary care service areas where provider caseloads exceed 3,000 children (Shipman et al., 2011). Health care providers in this region of the state may have seen children less frequently than providers in southern regions. Given the length of time between visits, it is possible that providers in the north may have moved to diagnosis sooner than those in southern regions of the state in order to ensure that children would receive timely services. It is unknown how provider caseloads may influence timing of ASD diagnosis, however exploring regional differences and the extent to which provider caseloads influence timing of ASD diagnoses may be an important implication of this study.
Previous studies have suggested disparities in age of diagnosis across geographic regions, with children in rural regions receiving later diagnoses than children in urban regions (Mandell et al., 2009; Shattuck, 2009). Using data from the Interactive Autism Network database, Rosenberg et al. (2011) reported that geographic region contributed 0.58% of the variance in age of diagnosis (n=7871). Rosenberg et al. (2011) suggest the need for initiatives to increase awareness of ASD, promote screening efforts, and increase access to early intervention in rural regions of the country.

**Provider Type.** The hypothesis that Provider Type would make a unique contribution to the variance of mean age at ASD diagnosis was not supported by this study. None of the specified Provider Types contributed unique variance when controlling for other variables in the full model (Model 7). However, in both northern and southern regions of New Hampshire pediatricians had the highest frequency of diagnostic office visits and in the full model Pediatric Medicine was approaching significance (p=0.054). Further study with a larger sample may provide important information about the influence of Provider Type on timing of ASD diagnoses. To date, there is a gap in the literature on this topic; however, in a survey administered by three pediatric practices in New York and New Jersey parents reported that a neurologist had assisted them with their child’s diagnosis, while 47% reported working with a developmental pediatrician (Harrington, Rosen, Garnecho & Patrick, 2006).

**Limitations**

There are several limitations of this study. First, insurance claims data capture specific health care information for those who are insured, but do not capture the experiences of the uninsured. Estimates of public and privately insured and uninsured children (0-18) in New Hampshire in 2010 included 78% insured by employer-sponsored or individual (commercial)
insurance plans, 18% insured by Medicaid (185% federal poverty level) and 5% uninsured (Kaiser Family Foundation, 2012). Socioeconomic and demographic differences in populations exist dependent on whether children are insured and type of insurance and results must be interpreted with caution.

Second, insurance claims data are susceptible to error due to inconsistencies in coding across settings and practices. The CPT code for developmental screening (96110) is recommended when an AAP-recommended screening instrument is used; however, even for those with insurance, the data may not have accurately captured all children who were screened using a standardized tool in New Hampshire during the study period. Further, it is unknown how pediatric providers utilize CPT code 96110 in their practices. Some providers prefer to screen children informally during well-child visits and code the visit as a “screening” visit (Crais, et al., 2010; unpublished raw data), while others use a standardized tool. While the AAP recommends the use of a standardized developmental screening instrument, the use of CPT code 96110 does not guarantee it.

Insurance claims data do not provide information about the specific screening instruments used or individual results of screening. Children who screened positive but did not receive a diagnosis of ASD, and children who received a differential diagnosis (where multiple diagnoses were possible) did not appear in these data. Data on race were unavailable, and ethnicity data were poorly coded; therefore the race and ethnicity variables were removed from the analyses. Claims data do not include information on severity of diagnosis. Children with more severe symptoms of ASD may have received an earlier diagnosis than those with milder expressions of the disorder.
Conclusion and Future Implications

Despite these limitations this study contributes several important findings. First, the mean age of ASD diagnosis in this study was 28.97 months (study period January 2007-December 2010). This is consistent with data from the NH Autism Registry, which shows a steady decrease in age of ASD diagnosis in the state between 2009 and 2011. Estimates at the national level suggest a mean age of diagnosis between 5 and 6 years. Thus, these preliminary findings are positive indicators that NH is progressing in its ability to identify children with ASD early. Continued examination of this trend with a larger sample will yield important information for families and primary care providers in the state.

Children in this study who were screened at more than one time point experienced later diagnoses. This suggests that these children may have presented with unclear developmental profiles leading providers to engage in a period of ‘watchful waiting’ between screenings and potentially delaying access to early intervention. A methodology comparing developmental screening profiles resulting in referral for early intervention with those that did not warrant referral could provide information about the practice of ‘watchful waiting’ and inform future efforts to identify children at risk for ASD at earlier ages.

In this study, geographic region made an independent contribution to timing of ASD diagnosis, accounting for 31% of the variance. Providers in northern regions of NH diagnosed children with ASD at slightly younger ages than those in southern regions and pediatricians in the study had the highest frequency of diagnostic office visits when compared to other provider types. Continued examination of regional differences in timing of ASD diagnoses by provider type is an important implication of this study.
For young children at risk for ASD the full year between 12 and 24 months requires especially close surveillance as early behavioral markers of ASD emerge during this time period (Baranek, 1999; Colgan et al., 2006; Zwaigenbaum, 2005); however, there is only one scheduled well-child visit (18 months) during this critical period. If a child at-risk for ASD misses the 18-month visit, then the potential for intervention is delayed. In addition, redundancies across the three sets of screening guidelines for children with developmental and behavioral disorders (AAP, 2006; AAP, 2007; AAP, 2010) have been identified and an alignment of screening and surveillance algorithms has been suggested (Marks et al., 2011). Other future directions include (1) examining timing of well-child visits for children with developmental risk factors, and (2) examining the role of parents in the developmental screening process, especially if they have a concern about their child.

Although beyond the scope of this study, administrative claims data contain information about related services (early intervention) received. A future study examining timing of early intervention services in relation to ASD diagnoses in NH has the potential to further inform practice. Continued efforts to measure screening practices through use of administrative claims data has the potential to increase utilization of developmental screening instruments and improve access to early intervention for young children with ASD.
### Appendix A

<table>
<thead>
<tr>
<th>Variables included in analysis</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study person identification</td>
<td>A unique numerical identifier randomly assigned by Institute for Health Policy and Practice</td>
</tr>
<tr>
<td>Relative birth month</td>
<td>Birth month/year relative to study month/year</td>
</tr>
<tr>
<td>Birthdates</td>
<td>Year and month of child’s birth</td>
</tr>
<tr>
<td>Date_service_from</td>
<td>Dates of service provided</td>
</tr>
<tr>
<td>Date_service_to</td>
<td>Dates of service provided</td>
</tr>
<tr>
<td>Gender</td>
<td>Categorical variable</td>
</tr>
<tr>
<td>County</td>
<td>County name (10 counties in NH)</td>
</tr>
<tr>
<td>Geographic region*</td>
<td>A dichotomous variable was created to define two geographic groups (urban and rural) by examining population estimates across the ten counties in New Hampshire.</td>
</tr>
<tr>
<td>Insurance eligibility</td>
<td>Categorical variable appearing in data by month</td>
</tr>
<tr>
<td>Provider specialty code</td>
<td>Provider Type</td>
</tr>
<tr>
<td>Procedural code</td>
<td>CPT, ICD-9, HCPCS Code</td>
</tr>
</tbody>
</table>

*Indicates a variable created for this analysis
References


Baranek, G.T., Personal Communication, October 17, 2012


McClain, M. Personal Communication, January 2012


SAS v. 9.3 (Cary, NC).


