

INSURANCE MANDATES FOR DIAGNOSIS AND TREATMENT OF CHILDREN  
AND ADOLESCENTS WITH AUTISM AND EVALUATIVE DATA SOURCES: A  
CASE STUDY OF TWO U.S. STATES

by

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A Capstone Submitted to the Graduate Faculty  
of Georgia State University in Partial Fulfillment  
of the

Requirements for the Degree  
MASTER OF PUBLIC HEALTH  
ATLANTA, GEORGIA 30303

**2015**

**APPROVAL PAGE**

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## ACKNOWLEDGEMENTS

First, I would like to express my sincere gratitude to my committee chair, Dr. Shanta Dube, for her continuous dedication throughout all stages of this project. Her experience, vision, and academic guidance were decisive to keep me motivated and focused during troubling times. My appreciation also goes to the other outstanding member of my committee, Dr. William Thompson. His collaboration went beyond the Capstone review: Dr. Thompson was a distinctive mentor that pushed me to mature my professional goals. Furthermore, I sincerely thank all the agencies that voluntarily informed this study and were decisive for the quality of its content.

Secondly, I must acknowledge the participation of some key protagonists in the construction of my critical thinking in public health, which is reflected in this project. Dr. Daniel Crimmins, for immersing me in the study of questions involving disability, determinant experience for many of my current and future career choices. Dr. Bruce Perry and Dr. Rodney Lyn for so brilliantly introducing me to the policy and structure of the U.S. healthcare systems and collaborating for the consolidation of my study focus as a public health scientist. And Pearly Dhingra for the uninterrupted motivation to keeping fighting for my wildest and most utopic philosophies in public health.

Lastly, and most importantly, I would like to dedicate this project and the MPH conclusion to my family and friends. Regardless of the physical distance, my parent's support and inspiration were the principal motivator that kept me moving forward with my objectives. Thank you also to my family, in-laws, and friends in the U.S., that helped me find security and warmth out of my comfort zone. Lastly, I doubted whether I could make it through the challenging and tough times in the past two years without my boyfriend Ben by my side. An unconditional love brought us together and is inspiring a beautiful journey in my career and personal realization.

## ABSTRACT

**BACKGROUND:** It is recognized among providers, parents and health organizations that the current health care system is unprepared for a rising number of children diagnosed with Autism Spectrum Disorder (ASD) worldwide. Meanwhile, differences in mandated insurance coverage for ASD across the U.S. could drastically impact the diagnosis and treatment strategies chosen by providers and families. **PURPOSE OF**

**RESEARCH:** The present case study aimed to review and compare policies and programs for children and adolescents with ASD in Pennsylvania (PA) and Georgia (GA), focusing on private insurance mandates. Additionally, the case study intended to identify and evaluate data sources that can be used to assess the implementation and impact of ASD insurance mandates in those states. **METHODS:** Key advocates and health agencies' representatives were contacted to collaborate in the identification of the state regulated initiatives and potential data sources that track children and adolescents with ASD. Insurance enrollment, pharmacy care, health care service utilization, and cost of care were the indicators used to evaluate data sources in their ability to evaluate the impact of the insurance mandates. **RESULTS:** PA showed a more comprehensive insurance mandate and state-driven health-related initiatives for children and adolescents with ASD than GA. Among the nine data sources reviewed, including claims and survey data, none provide essential indicators for a comprehensive evaluation of the impact of the ASD insurance mandate in PA or GA. **CONCLUSION:** The case study indicated that for GA and PA, ASD policy tracking and evaluation can be accomplished with some of the currently available data sources, however, important gaps in the surveillance of ASD-related outcomes exist. Thus, the study suggested that efforts towards more comprehensive data sources across all states is needed in order to evaluate ASD initiatives that inform ASD related- health policy and programs.

**KEYWORDS:** Evaluation Studies; Child Development Disorders, Pervasive; Insurance Coverage; Data Collection; Pennsylvania; Georgia.

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Albuquerque C.M.R., Neto P.L.S., Amorim M.L.P., Pires S.C.V. Pediatric epidemiological aspects of scorpionism and report on fatal cases from Tityus stigmurus stings (Scorpiones:Buthidae) in State of Pernambuco, Brazil. The Journal of the Brazilian Society of Tropical Medicine 46(4); Jul-Aug, 2013



**RELEVANT  
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THE STUDENT NETWORK FOR PUBLIC HEALTH LAW AWARD (10/2014)

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POSTER PRESENTATION (09/2011 and 10/2012)

**ET-UFPE HEALTH SEMINAR** RECIFE, PE/BRAZIL  
POSTER PRESENTATION (04/2012)

## TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS.....	i
ABSTRASCT.....	ii
LIST OF TABLES.....	x
LIST OF FIGURES.....	xi
CHAPTER	
I. INTRODUCTION.....	1
II. LITERATURE REVIEW.....	3
Definition and Epidemiology of Autism Spectrum Disorder (ASD).....	3
Best Practices in ASD Treatment.....	5
Antipsychotics and ASD Treatment.....	8
Service utilization and cost of ASD patients.....	9
Public Health Policies for ASD in the U.S.....	10
ASD in Pennsylvania and Georgia.....	12
Purpose of Research.....	13
III. METHODS AND RESULTS.....	15
Identification of U.S. states with different insurance coverage mandates for ASD.....	16
Comparison of states on ASD insurance coverage.....	17
Identification and comparison of data sources for tracking ASD insurance policies.....	23

Description of data sources that can assess the population-level impact of policies and programs in ASD-related outcomes.....	27
IV. DISCUSSION.....	30
Key findings.....	30
Implications and recommendations.....	31
Limitations.....	33
Conclusion.....	34
REFERENCES.....	36

## LIST OF TABLES

	<b>Page</b>
TABLE 1. Public Health Policies and Programs for children and adolescents with ASD in Pennsylvania and Georgia .....	18
TABLE 2. State ASD Insurance Coverage Mandate in Pennsylvania and Georgia...	22
TABLE 3 Indicators of Insurance policies used in the description of data sources...	23
TABLE 4 Data sources that track ASD insurance policies' indicators in Pennsylvania and Georgia.....	26

## LIST OF FIGURES

	<b>Page</b>
FIGURE 1. CDC's recommended framework for program evaluation.....	15
FIGURE 2. States Initiatives Map (Autism Speaks, 2014).....	16

# CHAPTER I

## INTRODUCTION

Autism spectrum disorder (ASD) is defined as an aggregation of diagnoses that were previously considered separate conditions: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified. A typical ASD patient presents signs of deficits in communication and social skills during early childhood. The prevalence of ASD has increased over the past several decades. In 2000, 1 in 150 children had prevalent ASD and this increased to 1 in 68 children in 2010, which has caused significant concern among the public health community (Baio, 2014).

The World Health Organization (WHO) released a meeting report on Autism Spectrum Disorder (ASD) and other developmental disabilities that intended to raise awareness and motivate "...innovative, integrated approaches for implementation of feasible, effective and sustainable intervention programs" (WHO, 2013). Health providers and parents recognize that the available health care system is unprepared in providing care to individuals with ASD. Even in nations with advanced care for ASD, there is an urgent need for consensus regarding the best approach to promote health in this population.

Because the biological mechanisms of ASD remain uncertain and a wide range of signs and symptoms encompasses ASD diagnosis, identifying treatment options is a challenging process for families, and the healthcare providers. Thus, building evidence-

based practices for ASD is the current focus of advocacy organizations and government agencies. The use of medication (Kumar et al., 2012) and early behavioral (Heyvaert et al., 2014) interventions have been the most traditional areas explored as “best practices”. Yet, some common treatments continue to be recommended without an assessment for the safety of the use in treating ASD (Schubar et al, 2014).

Current differences in mandated insurance coverage for ASD across the U.S. could drastically impact the treatment chosen by providers and families (Stein et al., 2012). Therefore, a comparison of health services and drug prescription claims across states may help researchers understand the impact of different mandates in the uses of “best practices” for treating ASD patients. As an example, Pennsylvania (PA), the 7th State to enact an ASD reform, passed one of the most comprehensive bills in the country in 2009 (The National Autism Association of Pennsylvania, 2008). Meanwhile, in Georgia (GA), the Autism insurance reform bills were first introduced in January of 2009 and, after several years of intense debate in the Senate and the House, had finally been version signed by GA’s governor only in April of 2015 (Autism Speaks, 2015).

The present study will closely review current mandates across the two previously mentioned states and the available data sources to potentially assess how policy may impact diagnosis and treatment of ASD. Health agencies, researchers and policymakers will benefit from this project by highlighting the strengths and limitations of current ASD insurance mandates and describing the available data collections that may be used to evaluate these practices and highlight in available data. Consequently, future research questions could be answered more objectively and gaps in the available data could be considered and addressed.

## **CHAPTER II**

### **LITERATURE REVIEW**

#### **Definition and epidemiology of Autism Spectrum Disorder (ASD)**

The 2013 Statistical Manual of Mental Disorders (DSM-IV) provides a guide for medical providers for diagnosing psychiatric outcomes and specifies a relevant update on the criteria for ASD (APA, 2013). Thus, a patient could be considered an ASD case when diagnosed within any four distinct disorders: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified. A comprehensive range of signs and symptoms are used for a more accurate recognition of cases, which may have a direct impact in the measurement of incidence in the population. Frequently, a typical Autism Spectrum case includes deficits in communication and social skills that are perceived during early childhood and that may also show different levels of severity.

To date, there has been no single factor implicated as a cause of ASD. In fact, research has suggested that there is a multiple factor causal model, that includes genetics (Huquet et al., 2013), environmental factors (Durkin et al., 2008) and their interaction (Kinney et al., 2010). Therefore, identifying specific risk factors for the prevention of ASD is still an area that is being carefully investigated. Furthermore, there is also no single test that can accurately diagnose ASD. The proper screening and early diagnoses of ASD depends on continuous and careful observation by caregivers and providers as well as a public access to information regarding ASD characteristics. The implementation of the 'Learn the signs Act early' campaign in U.S. has demonstrated a significant shift in



early detection of ASD through increasing knowledge about monitoring among parents and healthcare providers (Daniel et al., 2009).

Worldwide, the prevalence of ASD has varied drastically since the beginning of its initial identification as a separate condition in late 60's. Elsabbagh et al. (2012) reviewed international studies on ASD prevalence and stated that due to the stigma and structural barriers, low and middle income countries persist with ineffective surveillance systems for ASD. Therefore, the estimation of a current global median of 62 cases per 10000 people is possibly underestimated. Higher rates of ASD in the U.S. and European countries when compared with the rest of the world could largely be a result of methodological differences in the diagnosis and reporting of ASD (Zaroff & Uhm, 2012). However, the main discussion across countries is regarding the increase in ASD incidence rates and the concern about the best practices for diagnoses and treatment.

The exponential growth in ASD prevalence in the U.S. since 2000 has been only partly attributed to updates in the diagnostic criteria (Kim et al., 2014). Associated with changes in diagnosis, awareness of ASD among the general public and providers and increase in parental age (Liu et al., 2010) are estimated to correspond in nearly 50% of the increase in ASD prevalence. The other half of the exponential increase in the number of ASD cases remains unexplained and continuous to be the subject of numerous researchers (Buttar, 2014; Nemirovsky et al., 2015; James, 2014)

The epidemiology of ASD indicates that prevalence is higher among boys than girls, with the first diagnosis often happening around age 4 (Baio, 2014), and ASD is often comorbid with other mental health disorders (Levy et al., 2010). The previous

relationship found between ASD and socioeconomic factors was recognized to be the consequence of a social class bias in the service utilization among U.S. residents (Bhasin, & Schendel, 2007). Research focused on ethnic differences in the prevalence of ASD cases were almost exclusively conducted in the U.S. and suggested a higher risk among white Americans when compared with other ethnicities (Palmer, 2010). Among childhood mental and behavioral disorders in the U.S, ASD is one of the most frequent and debilitating (CDC, 2013; Matson et al., 2008).

### **Best practices in ASD treatment**

Accurate and early diagnosis of ASD is considered an important first step for choosing an effective treatment plan, which could vary drastically among individuals and age groups. The key challenge is in promoting interventions that reduce the morbidity associated with ASD and simultaneously improve well-being, which necessarily includes independence and socialization of ASD patients throughout their lives. When treating patients with ASD, a group of characteristics needs to be considered and assessed appropriately: community interaction, learning progress, self-care abilities, communication, co-occurrence of mental disorders, and other health-related issues (Mannion & Leader, 2013; Farmer & Aman, 2011). Because of the complexity of these group of characteristics that define ASD, treatment approaches tend to target in one or two of specific aspects (Patterson et al., 2012).

Recently, McLeod et al. (2015) conducted a systematic review and found that limited literature existed on the efficacy of interventions for the ASD population. Because of this finding, the authors highlighted the need to consolidate evidence-based

interventions for ASD as a priority for health providers, educators, and caregivers. To be considered evidence-based, an approach should promote “the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences” (APA, 2001). A consensus publication from the Missouri Autism Guidelines Initiative (2012) also focused on the reviewing evidence-based practices across the U.S. to provide an updated and improved guide from a systematic to an individual perspective of the treatment. This initiative assumes that “...providers need up-to-date information about intervention choices” and that government agencies should be in charge of building collaborations for the best exploration of those interventions.

Research that has focused on addressing early intervention for children under 3 years old has become popular and followed the current recommendation of ideal early detection of ASD cases. An extensive use of weekly therapy with several therapists and encouraging the parents’ constant participation are common among different treatment approaches in young children with ASD (Matson & Konst, 2014). Debates have suggested that influences of early treatments have the potential of “shaping the brain to be receptive to the social world, and in doing so, preventing or mitigating the symptoms and severity associated with ASD” (Sullivan et al., 2014). Yet, there is little evidence available regarding verified indications of how early interventions impact long term health outcomes for children with ASD.

Pharmacological approach have played an important role in the design of treatment plans for ASD (Coury et al, 2012). Medications often support the management of more severe and comorbidity-related symptoms and should be considered as a supplementary treatment option. Drugs don’t cure or prevent the occurrence of the core

symptomatology and are highly associated with deleterious side effects, for which ASD patients are more vulnerable. Those medications are often prescribed for purposes that have not been approved by the Food and Drug Administration (FDA) for treating mental disorders in children and adolescents (Devulapalli & Nasrallah, 2009). Meanwhile, existing research does not provide sufficient, reliable and methodologically strong evidence regarding the effectiveness and safety of the drugs (Cauffield, 2013). The use of medications and early behavioral treatment constantly frames the debates regarding the best practices for the management of ASD.

Specialists and parents have been anticipating the emergence of more complete therapeutic strategies and multidirectional evaluations. In 2013, Autism Speaks (AS), a leading organization in science and advocacy features of ASD community, hosted their national conference entitled “Treating the Whole Person with Autism: Care across the Life” that highlighted the following: the inclusion of Medical Homes principles in the ASD treatment, the application of Community-Based Systems of Services in the coordination of care for ASD patients, and the construction of a more supportive health care delivery system to this population (Coury et al., 2014). Bringing the care to the community and promoting a systematic patient-centeredness approach could help address the needs of ASD patients more holistically.

In previously implemented comprehensive treatment initiatives, ASD patients showed a higher level of satisfaction, experienced less unmet needs, and felt more empowered regarding their own care (Golnik et al., 2012). However, Knapp et al. (2013) discusses that children with behavioral health conditions often face several barriers in accessing services that are “...accessible, continuous, comprehensive, family-centered,

coordinated, compassionate, and culturally effective”. The vast range of symptoms and severity levels among ASD patients and the diversity of treatments available transform the individualized care into an urgent need.

### **Antipsychotics and ASD treatment**

Among drugs utilized in the management of ASD-related symptoms, antipsychotics are the most frequently studied; they were originally developed for the treatment of schizophrenia in the 1950’s. Antipsychotics reduce the dopamine effects in the brain, which are present in higher concentration in mentally-ill patients and are associated with irritability and psychotic episodes (Citrome, 2013). In general, two characteristics are currently used to describe antipsychotics: (1) first generation or conventional and (2) second generation or atypical. The use of first generation antipsychotics have a number of associated severe neural side effects (Peluso, 2012), including chronic involuntary body movements (dyskinesia). Among second generation agents, the side effects are less severe but still occur frequently, in particular weight gain (Almandil et al., 2013).

Currently, the only FDA-approved antipsychotics for the treatment of ASD are Risperidone and Aripiprazole, both second-generation agents. Risperidone was repeatedly tested using diverse methodological approaches and has been recognized to improve behaviors such as “irritability, aggression, self-injury and tantrums in autistic children and adolescents aged 5–16 years” (Malone, 2009). Aripiprazole, a drug that recently gained FDA approval, was verified to decrease disruptive symptoms in controlled trials involving children with ASD (Marcus et al., 2009). Increasing rates of

antipsychotic prescribing for very young children has been reported (Ofson, 2010) and in any given year nearly 40% of children with ASD receive an antipsychotic (Schubart, 2014).

Several challenges prevent the development of pharmaceutical treatment for ASD, which has led to an extensive body of research focused on other non-approved medications that will continue to be prescribed interchangeably. Antipsychotics have been tested less frequently among children and adolescents, which is due to safety concerns and apprehensions regarding the consequences of early exposure. Because of the common and often hazardous side effects, the prescription of Antipsychotics should be monitored closely, and when possible, avoiding chronic use. Furthermore, the lack of consensus across the country regarding the most effective drug strategy for ASD makes the monitoring of providers' practices and their health-related consequences difficult.

### **Service utilization and cost of ASD patients**

The healthcare system availability and accessibility could have a direct impact in the treatment strategies chosen for ASD patients. Elsabbagh et al. (2012) found that Medicaid coverage was directly correlated with higher rates of service utilization among ASD patients, when compared with private insurance, due to differences in coverage of services. Early diagnosis is also more likely to occur in areas with a high intensity of specialized physicians (neurologists and psychiatrists and medical schools (Kalkbrenner et al., 2012). Parents also perceived the health care system as being unprepared for dealing with the needs of children with ASD in terms of accessibility and quality of services (Jabery et al., 2014), which could be more troubling in rural areas (Murphy, 2012).

Some unusual features associated with ASD also affect patterns of health care services utilization. The presence of other mental health conditions in addition to the ASD diagnoses has been associated with a more intense use of services, poorer insurance coverage, and health-related outcomes (Ahmedani, 2012). The use of these services also differs within ASD patients depending on age and race/ethnicity, but are typically higher relative to the general population (Broder-Fingert, 2013; Cidav, 2013). Family income was also a predictor of higher rates of physician visits, emergency rooms visits, and hospitalizations, when compared with non-cases (Wu et al., 2015). These obstacles often lead to less integrated and ineffective treatment plans during the early years, which has a direct impact on the transitioning to adulthood and the patient's long-term well-being.

An increased demand for services among ASD patients is also associated with inflated health care costs. The cost of these services are covered in a variety of ways, including out of pocket, qualifying for publicly-financed (Medicaid) coverage, having private insurance, or relying on some combination of the three (Costlow et al., N.d.). Medical expenditures were predicted to be 4 to 6 times greater among children and adolescents with ASD when compared with those without an ASD diagnosis (Shimabukuro, 2008). During early childhood of individuals with ASD this healthcare cost is directly related with outpatient services utilization, while in older ages the health care cost is associated with the use of drugs and inpatient services (Shimabukuro, 2008). This prediction could be even more discrepant among patients enrolled in Medicaid (Wang, 2013). However, the cost associated with ASD goes beyond the health services utilization. An ASD diagnosis can incur health care expenses in excess of \$3,000 and an estimated total cost (education, caregiver time, therapy, and others) of \$17,081 per year

(Lavelle et al., 2014). Chiara et al. reported that for each additional [ASD related] symptom reported was associated with \$1,400 increase in costs per individual.

### **Public Health policies for ASD in the U.S.**

Since early 2000's in the U.S., public health policies related with ASD have received increased attention. At the federal level, enacting of the Children's Health Act of 2000 and the Combating Autism Act in 2006 are significant initiatives that support awareness, surveillance, research, training, and advocacy of ASD. More recently, The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014 expanded provisions of previous congressional bills by including the needs of transitioning ASD youth. Other bills that focus on rebuilding access and delivery of care, such as The Affordable Care Act (ACA), also include provisions that address several unmet needs of ASD and related conditions (Golden et al., 2014).

The U.S. Federalism model leaves states in a leadership position for the decision-making process of many public health related policies. The National Conference of State Legislatures commented in 2012 that "Several states have developed task forces or commissions to further study autism issues." Johnson et al. (2015) reviewed that policies in the state level translate local values and that could be a key cause for differences in the effectiveness of healthcare systems nationwide in addressing needs of ASD patients. Rzhetsky et al. (2014) suggested, in the attempt to build a framework for factors that affect ASD incidences in U.S. states, that "...the effect of state-level regulations [public health policies] involving ASD appeared relatively large in magnitude...".



Insurance coverage could be a primary obstacle for the broader application of best practices in the management of ASD-related symptoms (Stein et al., 2012). Thus, many states have focused efforts in ASD-related insurance reforms in an attempt to decrease healthcare barriers for patients and intensify the financial contribution of states to the cost of ASD treatment. Since Indiana's first law in 2001, 37 other states and 2 territories have enacted ASD-related insurance policies (Autism Speaks, 2015). However, the terms of coverage and eligibility criteria vary drastically within states, which could also have a direct impact in treatment patterns. Other states provide limited Autism mandates or include ASD patients in policies for mental health illness coverage (ASHA, 2015).

### **ASD in Pennsylvania and Georgia**

The primary aim of the Autism and Developmental Disabilities Monitoring (ADDM) Network is to understand Autism and other disabilities regarding their occurrence and characteristics in the U.S. (CDC, 2009). It is a program funded by Center for Disease Control and Prevention (CDC) and consists of 16 tracking sites, including GA and PA. For the surveillance year of 2006, using health records, PA found a prevalence of 8.4 ASD cases per 1,000 children aged 8 years old. For GA, using both health and education records, found a prevalence of 12 ASD cases per 1,000 children aged 8 years old. In the same report, those states discovered a similar median of age of first ASD detection (52 and 53 months). However, in the years following the first of ADDM surveillance, Pennsylvania and Georgia showed some differences in initiatives for the policy and management of ASD.

In 2008, PA passed a comprehensive bill (HB 1150) that requires both private insurances programs and medical assistance programs to cover specific behavioral therapy for ASD patients. Those covered benefits are capped at \$36,000 a year and are applied to individuals with ASD aged 21 years old or younger. The Pennsylvania Autism Insurance Act, also known as Act 62, has no lifetime benefits caps or visit limits. PA also chose to expand the Medicaid program and to implement provisions of the ACA that impact the ASD community as a whole. For example, ASD patients have guaranteed coverage of minimal health benefits, including behavioral health treatment with no lifetime or annual dollar caps (Bagley& Levy, 2014).

GA very recently passed an ASD insurance reform. In 2009, the first time an ASD insurance bill (called Ava's law) was proposed in GA, the House voted against it, suggesting a need for an intense review of its provisions. In that bill, ASD-related services would be covered for up to \$35,000 a year under Ava's Law (SB 397), which would not have been provided for patients covered by Medicaid. Currently, politicians and advocate groups continue to disagree on other provisions of the proposed bill, such as the use of therapeutic cannabis and the requirements for small companies, which has delayed its enactment. Meanwhile, the Medicaid program was not expanded in GA after the ACA came into effect in 2014. However, other ACA provisions that improve access to care, such as guaranteed coverage for individuals with pre-existing conditions, were adopted in GA and have the potential to positively impact many underserved groups such as ASD patients.

### **Purpose of Capstone case study**

A common concern among researchers, providers, and families who have a vested interest in the care of children and adolescent with ASD is identifying best practices for treatment. Currently, scientific studies on the effectiveness and quality of several pharmacological and non-pharmacological approaches are still underway. Thus, identifying current insurance and policy mandates for diagnosing, treating and managing children and adolescents with ASD is critical to understand current trends in a range of aspects related with ASD. This information is also critical for evaluating the impact of ASD practices and policies. Continuous monitoring and evaluation of policy coverage for ASD diagnosis and treatment is standard public health practice.

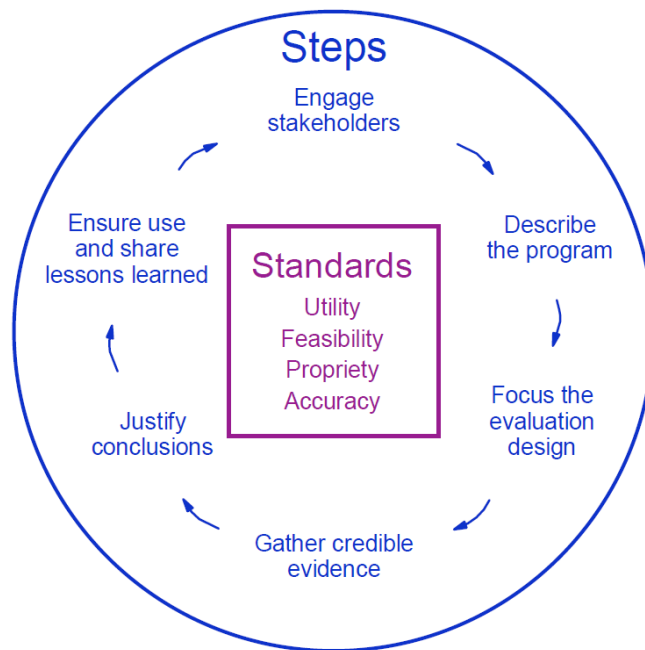
A primary goal of the current case study is to provide a comprehensive summary of the available information regarding how children and adolescents with ASD are diagnosed, treated, and managed, and what data systems would be used to track public health policies for ASD. Additionally, data sources that can be used to assess the impact of ASD policies will be identified and evaluated. To conduct this case study, two states with different insurance coverage mandates for ASD were identified: PA and GA. Three objectives guide this case study: 1) Compare and contrast ASD insurance coverage policies for two states, 2) Identify and evaluate data sources for tracking ASD diagnosis and treatment policies, 3) Identify and evaluate data sources that could assess the population-level impact of ASD policies and programs for a wide-range of ASD-related outcomes. The present case study provides groundwork for future studies focused on health services utilization, prescription drugs and insurance coverage among children and adolescents with ASD.

## CHAPTER III

### METHODS AND RESULTS

The present case study utilized the Framework for Program Evaluation in Public Health (CDC, 1999) during the construction of the methods to evaluate ASD-related policies and track data sources. The CDC's framework states that key steps for a strong evaluation (Figure 1) are interdependent and should be adapted to the program's needs. CDC understands the idea of program as "any organized public health action", such as the development and implementation of the ASD insurance mandate. The present case study was designed to serve as a component of a more comprehensive process evaluation of the impact of ASD insurance mandates in health indicators and outcomes of children and adolescents with ASD.

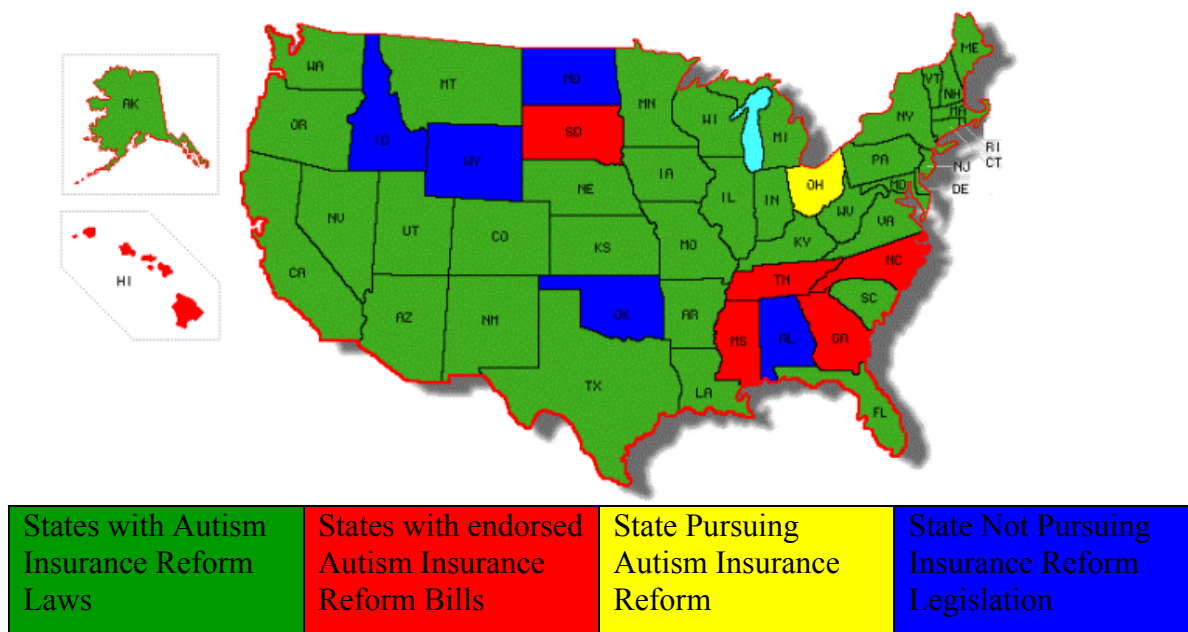
**Figure 1. CDC's recommended framework for program evaluation**



## Identification of U.S. states with different insurance coverage mandates for ASD

In 2014, Autism Speaks launched the “State Initiative Maps” (Figure 1), which reviewed the current status of ASD insurance mandate policies nationwide. For the purpose of this case study, two states were selected based on discrepancies in main terms of their ASD legislation (age group coverage, limit per year, and applicable groups) and because surveillance data was available for both of them from the Autism and Developmental Disabilities Monitoring (ADDM) research site. Thus, PA will be considered representative of the group of “States with Autism Insurance Reform Laws” and GA “States with endorsed Autism insurance reform bills.” This map was updated before the passage of GA’s mandate in April of 2015, but will still be considered for this case study because of the terms of these mandate have not yet been implemented.

**Figure 2. States Initiatives Map (Autism Speaks, 2014)**



## **1) Comparison of states on ASD insurance coverage**

To provide an accurate review of public health policies involving ASD that could impact drugs and health service utilization in the selected states, the following online sources were examined: Pennsylvania's Department of Health and Human Services and Georgia's Behavioral Health and Developmental Disabilities, Department of Community Health, and Department of Public Health. Furthermore, key advocates and health agencies' representatives were contacted to provide insights on the policies and programs in place for Georgia and Pennsylvania. The following list of organizations voluntarily informed this study:

- 1) Division of Birth Defects and Developmental Disabilities (CDC);
- 2) Satcher Health Leadership Institute;
- 3) Autism Speaks;
- 4) Association of University Centers on Disabilities (AUCD);
- 5) Morehouse Medical School;
- 6) Emory Autism Center;
- 7) Center for Leadership in Disability;
- 8) The Center for Autism;
- 9) Pennsylvania Department of Human Services;
- 10) Autism Services, Education, Resources and Training (ASERT).

In the early 2000's, PA intensified their efforts to more explicitly address the needs of individuals with ASD (Table 1). Initially, the creation of The Autism Task Force resulted in the implementation of the PA Autism Census Project and the Bureau of Autism Services (BAS) (Table 1). The BAS then conducted The PA Autism Needs Assessment and launched the Autism Services, Education, Resources and Training (ASERT) program (Table 2). PA also adopted Medicaid Waivers under the Home and Community Based Services (HCBS) program options that allow the provision of long term care services in home and community based settings. Under HCBS programs, the federal government "waives" Medical Assistance/Medicaid rules for institutional care in order for the state to use the same funds to provide supports and services for people in their own communities. Parents of children and adolescents may be eligible to apply for several waivers, but the Medicaid Waiver for Infants, Toddlers, and Families specifically targets the management of ASD in PA (Table 1). Since 1987, the Georgian interagency Babies Can't Wait (BCW) has provided early interventions and has been focusing its efforts on Autism during recent years (Table 1). In 2001, the HB 565 law required insurance plans in GA to include ASD in the same benefits group as those individuals with other neurological disorders (Table 1). GA also has adopted some HCBS Medicaid waivers that may impact the care of children and adolescents with ASD, specifically the Comprehensive Supports waiver program (Table 1).

**Table 1. Public Health policies and programs for children and adolescents with ASD in Pennsylvania and Georgia**

State	Year	Public Health policy or program
PA	2003	The Autism Task Force Created by the Department of Public Welfare. Included over 250 family

	<p>members, providers, educators, administrators and researchers that developed a plan for a new system for individuals with ASD and their families.</p> <p>(PA Department of Public Welfare Commonwealth of Pennsylvania. Autism Task Force: Final Report. (2004). Retrieved from: <a href="https://www.paautism.org/">https://www.paautism.org/</a>)</p>
<b>2005</b>	<p><b>Pennsylvania Autism Census Project</b></p> <p>First conducted by the Department of Public Welfare to estimate the number of individuals living with ASD in Pennsylvania and the demographic characteristics and scope of needs for ASD-related services and programs. The census was updated in 2013.</p> <p>(PA Department of Public Welfare, Bureau of Autism Services. Pennsylvania Autism Census Project: Final report. (2009). Retrieved from: <a href="http://www.dhs.state.pa.us/">http://www.dhs.state.pa.us/</a>)</p>
<b>2006</b>	<p><b>1915(c) HCBS waivers program</b></p> <p><b>Medicaid Waiver for Infants, Toddlers, and Families</b></p> <p>Provides services to children from 0-3 years old who are in need of Early Intervention services and require the level of care provided in an Intermediate Care Facility for Persons with Mental Retardation or Other Related Conditions (ICF/MR-ORC). Children eligible to apply should have family income limit of 300 % Federal Benefit Rate</p> <p>(Pennsylvania Dep. Of Human Services. Waiver Information. Retrieved from <a href="http://www.dhs.state.pa.us/learnaboutdhs/waiverinformation/infanttoddlersandfamilieswaiver/index.htm">http://www.dhs.state.pa.us/learnaboutdhs/waiverinformation/infanttoddlersandfamilieswaiver/index.htm</a>)</p>
<b>2007</b>	<p><b>Bureau of Autism Services (BAS)</b></p> <p>Created as a recommendation of the Autism Task Force Administred by the Department of Human Services. Aims to develop and manage services and supports to improve the quality of life of individuals living with ASD and their families/caregivers.</p> <p>(Bureau of Autism Services. (n.d.). Retrieved March 8, 2015, from <a href="http://www.dhs.state.pa.us">http://www.dhs.state.pa.us</a> )</p>
<b>2008</b>	<p><b>Autism Services, Education, Resources and Training (ASERT)</b></p> <p>Maintained by the Bureau of Autism Services in a partnership with medical, research, and services centers. Intends to connect existing resources and key expertise to address regional gaps in effective services and supports. ASERT activities are driven by PA Autism Needs Assessment findings.</p> <p>(ASERT Overview. (n.d.). Retrieved March 8, 2015, from <a href="http://www.paautism.org/en-us/asert/asertoverview.aspx">http://www.paautism.org/en-us/asert/asertoverview.aspx</a>)</p>



	<b>2008</b>	<p align="center"><b>Autism Insurance Act (Act 68)</b></p> <p>PA was the 7<sup>th</sup> state in the U.S. to enact an insurance regulation for individuals with ASD. The bill requires health insurance policies and medical assistance programs to cover up to \$36,000 for the diagnosis and treatment of ASD in individuals younger than 21 years of age.</p> <p>(Autism Speaks. SUMMARY OF PENNSYLVANIA AUTISM INSURANCE REFORM LAW PROVISIONS. 2009. Retrieved from: <a href="https://www.autismspeaks.org/advocacy/helpful-links/pennsylvania-helpful-links">https://www.autismspeaks.org/advocacy/helpful-links/pennsylvania-helpful-links</a>)</p>
	<b>2011</b>	<p align="center"><b>PA Autism Needs Assessment</b></p> <p>Conducted by the Bureau of Autism Services and ASERT to have a deeper understanding, on a local level, of specific needs of children and adults across the lifespan.</p> <p>(PA Autism Needs Assessment: A Survey of Individuals and Families Living with Autism. (n.d.). Retrieved March 8, 2015, from <a href="http://www.paautism.org/resources">http://www.paautism.org/resources</a> )</p>
<b>GA</b>	<b>1987</b>	<p align="center"><b>Babies Can't Wait (BCW)</b></p> <p>BCW is a statewide interagency of early intervention services for children with disabilities such as ASD, their families, and providers. It was established in GA to follow requirements of the Individuals with Disabilities Education Act (1997).</p> <p>Georgia Department of Public Health. Babies Can't Wait GA. Retrieved from: <a href="http://dph.georgia.gov/Babies-Cant-Wait">http://dph.georgia.gov/Babies-Cant-Wait</a>)</p>
	<b>2001</b>	<p align="center"><b>H.B. 565</b></p> <p>Under HB 565, health insurance plans that provide benefits for neurological disorders must cover the same benefits, including the scope of treatment for individuals diagnosed with ASD.</p> <p>(Georgia General Assembly. House Bill 565. Retrieved from: <a href="http://www.legis.ga.gov/Legislation/20012002/2929.pdf">http://www.legis.ga.gov/Legislation/20012002/2929.pdf</a>)</p>
	<b>2008</b>	<p align="center"><b>1915(c) HCBS waivers program</b></p> <p align="center"><b>Comprehensive Supports waiver (COMP)</b></p> <p>It was designed for people who need a full range of out-of home services or intensive in-home services. Community residential and alternative services are only available in the COMP waiver. The alternative services include Applied Behavioral Analysis and other therapies for ASD.</p> <p>(Adams D. 2009. Constructing a good life through Understanding the now and comp waivers, A Ready Reference for Families and Individuals with Disabilities. Retrieved from: <a href="http://www.dfmc-georgia.org/resources/documents/now_and_comp_waivers.pdf">http://www.dfmc-georgia.org/resources/documents/now_and_comp_waivers.pdf</a>)</p>

	<b>2009</b>	<p align="center"><b>Study Committee on Autism</b></p> <p>The Study Committee aims to discuss issues related to availability, access, and affordability of health care insurance covering ASD. It was proposed by Sen. Tommie Williams, leader of the ASD Insurance bill proposal, through several committees since 2009.</p> <p>(Easter Seals, Inc. 2012 State Autism Profiles GEORGIA. 2012. Retrieved from: <a href="http://es.easterseals.com/site/DocServer/2012_Autism_Georgia.pdf?docID=155459">http://es.easterseals.com/site/DocServer/2012_Autism_Georgia.pdf?docID=155459</a>)</p>
	<b>2015</b>	<p align="center"><b>Ava's Law</b></p> <p>Ava's Law was first introduced by Georgia's Senate (SB 161) in 2009 to require full coverage of ASD treatment services for children aged 6 years old and younger. The final version was released in the General Assembly f 2015. The bill was approved by the House and Senate in 2015 and signed by GA's Governor in early April of the same year.</p> <p>(Autism Speaks. Georgia Bill History. 2014. Retrieved from: <a href="https://www.autismspeaks.org/bill-history/advocacy/georgia-bill-history">https://www.autismspeaks.org/bill-history/advocacy/georgia-bill-history</a>; William, D. 2015. Autism bill gains final passage from General Assembly. Atlanta Business Chronicles Retrieved form: <a href="http://www.bizjournals.com/atlanta/blog/capitol_vision/2015/04/autism-bill-gains-final-passage-from-general.html">http://www.bizjournals.com/atlanta/blog/capitol_vision/2015/04/autism-bill-gains-final-passage-from-general.html</a> )</p>

In 2008, PA passed the comprehensive Autism Insurance Act that mandated private insurance companies to cover services for individuals with ASD up to 21 years old (Table 2). PA's mandate is applicable to individuals under large business plans (more than 50 employers), in PA Children's Health Insurance Program (CHIP), and to a limited extent the Medicaid program. In addition, there are no caps in the number of visits or a life-long benefit limit for individuals with ASD under the PA mandate. It is important to note that in PA, children and adolescents may be eligible for the Medical Assistance program (Medicaid) if meeting the income requirements or the Social Security Administration (SSA) definition of disability. The HB 1150 also established guidelines for children enrolled in Medical Assistance, PA Department of Public Welfare will cover the costs that exceed the Medicaid limit.

The first insurance mandate bill for individuals with ASD in GA, named Ava's Law, was proposed in 2009 and targeted children up to 6 years old (Table 2). Recently, GA's legislature postponed the passage of Ava's Law for more than 2 years and the law in place is considered a conservative in terms of coverage by ASD advocate groups in the U.S., especially because of the limited age group included. A final version of the bill was passed in the General Assembly in late March of 2015 and the Governor's signature in early April, during the World Autism Awareness Day. The coverage of behavioral health treatment, which is often denied by private insurance companies, is one of the main features of the bill passed in GA. Ava's Law does not include provisions that address services for individuals under the Medicaid program and, currently, individuals with ASD enrolled in Medicaid are covered by the HCBS waivers program.

**Table 2. State ASD insurance coverage mandate in Pennsylvania and Georgia**

	<b>Pennsylvania</b>	<b>Georgia</b>
<b>Bill</b>	Autism Insurance Act (HB 1150)	Ava's Law (HB 309/SB 191/HB 559)
<b>Year of Enactment</b>	2008	2015
<b>Age group coverage</b>	0-21 year old	0-6 year old
<b>Benefit limit</b>	\$36,000/year	\$30,000/year
<b>Applicable to small business and individual plans</b>	NO	YES (over 10 members)
<b>Applicable to large business (51 member or more)</b>	YES	YES
<b>Applicable to Medicaid enrollers</b>	YES	NO
<b>Lifetime benefit limit</b>	NO	YES (\$200,000)
<b>Visits limit</b>	NO	NO
<b>Services coverage</b>	Medically necessary services (1) Prescribed medications	Medically necessary services (1) Prescribed medications

	and related tests (2) Psychiatric care (3) Psychological care (4) Rehabilitative care, including applied behavior analysis (5) Speech, occupational and physical therapy	and related tests (2) Psychiatric care (3) Psychological care (4) Rehabilitative care, including applied behavior analysis (5) Speech occupational and physical therapy
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## 2) Identification and comparison of data sources for tracking ASD insurance policies

### Indicators

In the process of identifying data sources that could track insurance policies for ASD in the selected states, the main resources used were Georgia State University Library research tool and librarians, CDC's National Center for Health Statistics, and informing organizations. Inclusion criteria for evaluating data sources in this case study include: (1) represent individuals or groups from PA and GA, (2) distinguish children and adolescents with an ASD diagnosis, and (3) track two or more indicator of the insurance policies for ASD. The indicators of interest included: insurance enrollment (private and public funding), drugs prescription and dispensing (pharmacy care), health care services utilization (ASD-related exams, psychiatric care, psychological care, rehabilitation care, and therapeutic care), and cost of care (Table 3)

**Table 3. Indicators of insurance policies used in the description of data sources**

Indicators	Definition*
<b>Insurance enrollment</b>	The data source identifies the type of insurance enrollment plan. Private and public insurance enrollers could be distinguished.

<b>Drugs prescription and dispersion (pharmacy care)</b>	The data source provides information on drugs prescription and/or dispersion. The type of drug (generic or commercial IDs) is provided. Drugs used for the treatment of ASD-related symptoms could be identified.
<b>Health care service utilization*</b>	<p>The data source provides information about health care services utilized. Setting, provider, and/or service provided could be accessed and discriminated as:</p> <p>(1) ASD-related exams: diagnostic assessment of autism spectrum disorders;</p> <p>(2) Psychiatric care: direct or consultative services provided by a physician who specializes in psychiatry;</p> <p>(3) Psychological care: direct or consultative services provided by a psychologist;</p> <p>(4) Rehabilitative care: professional services and treatment programs, including applied behavioral analysis, provided by an autism service provider to produce socially significant improvements in human behavior or to prevent loss of attained skill or function;</p> <p>(5) Therapeutic care: services provided by speech language pathologists, occupational therapists or physical therapists</p>
<b>Cost of care</b>	The data source provides cost of health care service and pharmacy care prescribed and/or utilized. Copays may also be accessed.

\* Definitions were retrieved from the ASD insurance bills.

## Data sources

The National Center for Health Statistics (NCHS) provides several public-use data sets. Considering the inclusion criteria for the present study, the data from the following NCHS' studies were evaluated: the National Ambulatory Medical Care Survey (NAMCS), the National Hospital Ambulatory Medical Care Survey (NHAMCS), the National Health Interview Survey (NHIS Sample Child), National Survey of Children's Health (NSCH), and the National Survey of Children with Special Health Care Needs

(NS-CSHCN) (Table 4). The data sources found using GSU Library Tool (Statistical Information and Data on children and adolescents health) and suggested by the informing organizations were the Medicaid Analytic Extract (MAX), The Healthcare Cost and Utilization Project (HCUP State-Specific: Inpatient Databases, and Emergency Department Databases), The Medical Expenditure Panel Survey (MEPS Insurance/Employer and Medical Provider Components), and MarketScan databases (Medicaid and Commercial Claims and Encounters) (Table 4). Other data sources that track children and adolescents with ASD, such as data from the Study to Explore Early Development, the Autism and Developmental Disabilities Monitoring Network and PA Autism Census, were also proposed but not included in this analysis because insurance policy indicators were not included. Table 5 evaluates data sources in the capacity of monitored ASD insurance policies in Pennsylvania and Georgia using indicators described in Table 3.

**Table 4. Data sources that track ASD insurance policies' indicators in Pennsylvania and Georgia**

Data source (Years released until date) Sponsored agency	PA	GA	Insurance enrollment	Drugs prescription	Health care service Utilization					Cost of Care	Main limitations of the data source
					ASD-related exams	Psychic. Care	Psycho. care	Rehab. care	Therap. care		
<b>NAMCS</b> (1993-2014) CDC/NCHS	X*	X*	X	X		X	X				Only includes data related to office-based physicians' visits. It is nationally representative survey data.
<b>NHAMCS</b> (1993-2014) CDC/NCHS	X*	X*	X	X		X	X				Only includes data related to ambulatory care services. It is nationally representative survey data.
<b>NHIS Sample child</b> (1997-2014) CDC/NCHS	X*	X*	X	X		X	X		X	X****	It is a nationally survey data.
<b>NSCH</b> (2003-2011/12) USDHHS, HRSA, MCHB	X	X	X	X	X***	X	X	X	X	X****	It is a nationally telephone surveys data.
<b>NS-CSHCN</b> (2001-2009/10) USDHHS, HRSA, MCHB	X	X	X	X	X	X	X	X	X	X****	It is a nationally telephone surveys data.
<b>MAX</b> (2002-present) MMIS	X	X	X**	X	X***	X	X	X	X	X	Only includes Medicaid and CHIP enrollers. Does not collect data on exams and therapies.
<b>HCUP State-Specific Databases</b> (1990-2012) AHRQ	X	X	X	X		X				X	Only collects data related to hospitals and emergency care.
<b>MEPS</b> (1996-2014) USDHHS/CDC	X	X	X	X		X	X	X	X	X	It is nationally representative survey data.
<b>MarketScan</b> (1994-2014) TRUVEN®	X	X	X	X	X***	X	X		X	X	Only collects data related with services coverage under insurance. Behavioral therapies are often unrepresented.

\*Nationally representative data sets that provide ZIPCODE and could be subgrouped for each state. \*\* Includes Medicaid and CHIP enrollers.

\*\*\* Provide information on general mental health/behavioral exams. \*\*\*\* Provide information regarding general expenditure or cost barriers

### **3) Description of data sources that can assess the state-level impact of insurance policies in ASD-related outcomes**

MAX, HCUP and MarketScan are claims data sources that gather information from medically attended visits in different care settings (Table 4). One advantage of claims data is the reliability of the outcomes (it is based on medical records) and some disadvantage are the fragile generalizability (could only provide inferences to a specific group) and the fact that ASD diagnosis is not commonly done in a systematic manner. MAX data are collected in the state's Medicaid Management Information System (MMIS), which is based on different states' Medicaid programs and reported to the federal statistical system. MAX contains variables from inpatient admissions, long-term care, pharmacy, and other medical services coded in the Healthcare Common Procedure Coding System (HCPCS). Examples of variables that could track ASD insurance policy indicators are: Medicaid/CHIP enrollment plan, provider type, billing information (deductible, third party payment, coinsurance, etc.), mental health admissions, psychiatric services, therapies, early periodic screening, and drugs prescribed.

The collection of HCUP State-Specific Databases is sponsored by the Agency for Healthcare Research and Quality (AHRQ) and provides claims related to hospitalizations (even psychiatric) and emergency care. HCUP contain information regarding insurance coverage, codes to all services provided during the hospital visit, and their respective cost. However, because it does not encompass primary care and specialty setting, HCUP lacks the tracking of claims related to those services (ASD-related exams and psychological, rehabilitative, and therapeutic care). Lastly, MarketScan offers the largest convenience sample available among private databases for individuals under large



employer-provided health insurance in the U.S. It is more comprehensive because it captures the full variety of care in almost all settings (physician office visits, hospital stays, and detailed pharmacy care). MarketScan could also allow the longitudinal tracking of claims in a same group of individuals. Conversely, because it only computes services covered by insurance policies, it cannot track the use of services that are commonly not covered, such as behavioral services.

The other data sources reviewed in the present study collected data through surveys. This type of data present better external validity (better to draw conclusions about the population) than claims data but provides less specific outcomes to the target population. NAMCS and NHAMCS have a similar annually sampling approach. NAMCS track visits to non-federal employed office-based physicians, who completed the survey. NHAMCS collect data on the utilization and provision of ambulatory care services by the implementation of a patient record that is filled by the facility's staff. Both data sources include insurance coverage type and drugs prescribed and identify mental health services by the collection of data on the type of facility, provider, and treatment (such as psychotherapy or mental health counseling).

The NSCH and NS-CSHCN are both telephone surveys sponsored by a cooperative agreement from the U.S. Department of Health and Human Services (USDHHS), Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) and represent non-institutionalized children ages 0-17 in the national and state level. Those datasets include insurance and health care access, prescription drugs, mental health service utilization (including behavioral services), and questions regarding additional costs for services not covered under the insurance plan.

The NSCH serves as a supplement for the NS-CSHCN. The latter includes additional information regarding access to coordination of care, patient-centered services, adequacy of healthcare coverage, and children with disabilities' unmet needs (including financial barriers).

NHIS data is collected through an annual cross-sectional household interview survey and serves as the principal source of information for a broad range of health topics in the U.S. The child section of the NHIS Sample reports health-related events involving children living in the household. Questions regarding the insurance coverage, mental health related drugs prescription, access to mental health providers and therapeutic care are included. By tracking financial barriers in accessing to specific ASD-related services, this sample represents a subjective reports on cost of care. Finally, MEPS, which is a subsample of the NHIS, comprises a household component (with data from individual households and their members and supplemented by data from medical provider) and includes an additional insurance component (survey of employers that provide data on employer-based health insurance). The household component provides information on use and access of medical services, prescribed medicine and health insurance coverage. The insurance component collects information regarding the financing of health expenditures through an establishment survey and a health insurance survey in the private and state governments sectors.

## CHAPTER IV

### DISCUSSION

#### **Key findings**

Differences between PA and GA regarding state initiatives that address the needs of individuals with ASD go beyond the characteristics of their insurance mandates. Chronologically, GA was the first one to provide services that would reach the ASD population with the implementation of BCW in 1987 and H.B. 565 in 2001. However, GA's efforts slowed down in the 2000's even when the first ASD insurance policies began to pass in other states. Meanwhile in PA, the creation of a The Autism Task Force in 2003 triggered a consistent development of programs, surveillance and policies. Thus, the current study shows that the presence of less state-driven health-related initiatives that target children and adolescents with ASD may tend to coexist with delays in the passage of an ASD insurance mandate and the inclusion of more conservative provisions in the bill.

In the review of the ASD insurance mandates, an existence of important differences in PA's and GA's current bills were detected. Individuals may not be covered when in self-insured or small business health plans in PA and when under Medicaid or over 6 years of age in GA. Nonetheless, the present case study indicated that both bills address crucial pieces of the management of ASD symptoms, especially behavioral services (including Applied Behavioral Analysis). Many insurance companies have labeled those services as "experimental" and excluded them from coverage (Hansel, 2013). Yet, an intensive and comprehensive behavioral treatment, especially during early

childhood, drastically improves the actions and skills of individuals with ASD through their lives (LeBlanc & Gillis, 2012). Behavioral therapy accounts for a good portion of the out-of-pocket medical expenditure for parents of children and adolescents with ASD, which is closely related with health-insurance coverage (Parish, 2015).

In this case study, there was no evidence that the data sources reviewed provide comprehensive indicators that can be used to analyze the impact of insurance policies in PA or GA. In particular, there were larger gaps in indicators for ASD-related exams and behavioral therapies, which could compromise the measurement of health-related outcomes associated with those healthcare services. The cost of care indicator could only be tracked in detail in less than half of the data sources, which could compromise the assessment of the economics of the insurance mandates. Furthermore, many data sources were limited because of the specific settings in which the data were collected (ambulatory care, physician's office, etc.). Therefore, this case study indicates an urgent need for data collection systems at the state level that can appropriately represent children and adolescents with ASD and that can also assess the impact of insurance policies and programs among this population.

### **Implications and recommendations**

Based on the findings from this case study, the selected states could benefit from a different set of recommendations due to discrepancies in their mandates' provisions and implementation. For example, through this evaluation of data sources, PA could better understand the type of insurance plans, the utilization of services and drugs, and the cost of treatment among children and adolescents with ASD. To date, there is only one study

that evaluated the impact of the ASD mandate in PA (Stein et al., 2012). Stein et al., 2013 used claims data from a managed behavioral health organization to understand the changes in the service utilization among Medicaid enrollers after Act 68. PA will be able to focus their efforts on addressing these specific gaps in the available data sources by addition specific questions regarding service utilization, drugs prescription, and cost of care in the Autism Census Project. Until those gaps are addressed, many questions regarding the effects and appropriateness of the policy in the entire ASD community of PA will remain unanswered.

GA could use the findings from this case study in a differently manner. For example, GA can utilize the data sources reviewed in the present study to better understand the demand for healthcare and the trends in the treatment for ASD. This is especially critical given that GA just passed (April, 2015) an ASD insurance bill. Thus, GA has an opportunity to revise indicators so that an evaluation of the insurance policies could be properly conducted. The present study may also contribute to intensifying the demand for a state-level strategic plan for ASD and for initiatives that address the health needs of children and adolescents with ASD in GA. The Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) was a CDC initiative that focused on estimating the prevalence of developmental disabilities, including ASD, and served as the model for creation of ADDM Network in the U.S. GA could utilize some features of the methodology of this surveillance system to create a state service that tracks the policy-related indicators as additional measures of interest. MADDSP identifies children who are or will turn 8 years of age within the year of interest through an active record review at multiple health and education sources. Intending to understand

the individuals with ASD and their specific healthcare needs and treatment trends in Georgia, the proposed state-driven surveillance system could be collecting variables to address the gaps in the current data sources.

The present case study can also serve as a model to evaluate policy tracking and health-related impact of ASD insurance policies among children and adolescents with ASD in other states. A similar analysis could be replicated in other states, considering that little evidence exists regarding the effectiveness of ASD insurance laws on improving health outcomes in the target population. Tracking the impact of existing state policies and programs is crucial to continue to improve the discussion regarding the best practices for the management of ASD. States play a central role in the prediction of cost savings and long-term consequences of their initiatives and should utilize this case study in their process of building those predictions.

### **Limitations of the case study**

It is important to note some limitations of this case study that could implicate the quality of the findings and the ability to reach the study objectives more effectively. First, the study did not review programs delivered by non-governmental entities in PA and GA that could also affect the service utilization and assist in the surveillance for individuals with ASD. Even though the study focused on state-regulated initiatives, the knowledge about those other resources could have provided a more accurate picture of initiatives available for children and adolescents with ASD in PA and GA. Furthermore, the current study did not examine specific measures used to track indicators of the insurance mandates in the data sources that were reviewed. Future studies can take a more granular

examination of the indicators and specific measures as outlined in CDC Best Practices for Evaluation (CDC, 1999). While it is a limitation it is also fodder for future efforts to properly examine the effectiveness of state-level mandates on ASD coverage.

Lastly, the study did not address the possible impact of some federal initiatives that focus on children and adolescents with ASD and that include provisions that are mandated in states. The Autism Collaboration, Accountability, Research, Education and Support (CARES) Act (2014) reauthorizes the Combating Autism Act (2006) and dedicates resources for research, surveillance, and services for individuals with ASD in all age groups (Williams, 2014). The Achieving a Better Life Experience (ABLE) Act (2014) enacted a tax-free savings account for individuals with disabilities; the Act serves as a supplemental program to private insurance and Medicaid (NDI, n.d.). The Autism Care Demonstration (ACD) (2014) guaranteed the coverage of applied behavioral analysis services for individuals with ASD enrolled in TRICARE health plans (TRICARE, n.d.). Lastly, the Affordable Care Act (ACA), fully implemented in 2014, includes requirements to improve access and affordability of healthcare for individuals with ASD (Autism Speaks, n.d.).

## **Conclusion**

Despite some of the stated limitations, the present study is an important resource for state public health agencies and public health researchers because of novelty in assessing indicator tracking for public health policy and a review of available data sources for evaluation purposes. The data Quality Campaign (2010) highlights the importance of connecting policy and data, indicating that states "...need to prioritize and

elucidate the critical questions and issues that data systems must answer.” Furthermore, this study’s review of policies, programs, and the data sources was the result of collaboration between important stake holders, such as health and government agencies, non-profit organizations, and universities that are intensively involved in the discussions regarding ASD insurance coverage and related outcomes in the selected states. Finally, the case study also provides key short and long-term recommendations to states that could impact the management of the ASD-related challenges in those settings



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