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Autism: Association Between Autism and Parenting Stress

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Abstract

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Autism is a developmental disorder, whose etiology is still an active research. Objectives of this study are to identify: risk factors of parenting stress; statistical tools for analysis and interpretations of data to ascertain and reinforce risk factors; and recommendations to mitigate parenting stress of autistic children. Data: National Survey of Children with Special Care Needs (NS-CSHCN), 2005-06. Analysis was performed on NS-CSHCN (n=40,723). Among parents with autistic children (n=2,123), the highest adjusted odds of stress were reported associated with primary language (OR= 9.44), insurance (OR=0.34), and Respite care (OR=3.71). Parents with non-autistic children (n=38,133) was the reference population with 467 missing values. Recommendations: Re-evaluation to improve provider language services especially for CSHCN; Family centered public health delivery rather than patient-provider interactive approach.

AUTISM: ASSOCIATION BETWEEN AUTISM AND PARENTING STRESS

(Data from National Survey of Children with Special Care Needs, 2005-2006)

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AUTISM: ASSOCIATION BETWEEN AUTISM AND PARENTING STRESS

(Data from National Survey of Children with Special Care Needs, 2005-2006)

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CHAPTER 1

INTRODUCTION

Summary

It has been observed that autism in children ages zero to seventeen years has become the most common among the group of developmental disorders classified as “autism spectrum disorders” (ASDs). Other types of such disorders include Asperger syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder, not otherwise specified (usually referred to as PDD-NOS). Autism, sometimes referred to classical autism, remains the fastest growing among the ASDs. Similar to CDC 2008 figures, the National Institute of Neurological Disorders and Stroke reported in the 2009 update of “Autism Fact Sheet” an estimated “three to six children out of every 1,000 to have autism. Males are four times more likely to have autism than females”. (National Institute of Neurological Disorders and Stroke, NINDS, United States of America Department of Health and Human Services, USDHHS, 2009).

Autism is characterized by three major features ranging in impact from mild to disabling: (a) difficulties with social interaction, (b) problems with verbal and nonverbal communication, and (c) repetitive behaviors or narrow, obsessive interests. A parent may notice that from infancy, a baby with autism may not respond to people or focus intently on one item to the exclusion of others for long periods of time contrary to the normal behavior of children of the same age group. Medical testing and observation reveals “food allergies for autistic children like frequent diarrhea, bloating, low blood sugar, excessive sweating, redness in the ears and face, rhinitis (runny nose), the inability to

regulate the body temperature, and dark circles under the eyes are common” (Evans, 2006). Consequently, parents may decide to contact a primary health physician (PCP) for help, but there is a possibility that the first contact PCP may lack adequate expertise to help the parents. As the child develops, parents may notice further that autistic children may fail to respond to their name and often avoid eye contact with other people. Some autistic children may engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-banging (Evans, 2006). Parents may start reducing working hours in order to care for and explore other ways of helping the child. They may look for referral to see a specialist and discover difficulties with insurance and social support. Parents of autistic children may be teenagers having first time experience caring for autistic children. They may have language barrier or lack adequate education to look for information elsewhere, while some parents may fall on the internet for information. They may be anxious and frustrated about the worsening health symptoms and apparent disappointments from both PCP and insurance companies. These pieces of empirical evidence about parents of autistic children are confirmed by scientific studies, which suggest that “having a child with autism has a negative impact on maternal psychological functioning, but no large-scale, population-based studies are available” (Montes and Halterman, 2007).

Private organizations like Autism Speaks, Autism Society of America, The National Autistic Society, Organization for Autism Research, Southwest Autism Research & Resource Center and other advocacy groups are making attempts to provide the needed funds for research and information for parents and the general public, but

these efforts require some regulation and legal framework to succeed. The purpose of this thesis is to ascertain and reaffirm some of these difficulties parents face dealing with autistic children, in an attempt to raise awareness for policy makers to double-up efforts to provide the nationally recognized regulatory and legal framework to support these organizations.

This thesis focused on data from National Survey of Children with Special Care Needs, 2005-2006. The aim is to study predictive variables relating to parenting stress, and to investigate if such stress indicators are at odds with parenting autistic children ages seventeen years or younger living in the United States of America. The study utilized predictive variables such as those relating to access to health care, problem with insurance, communicative and cultural barriers and extended hours of home care with attendant job loss and economic issues. Demographic predictive variables such as age, gender, level of education and socio economic status of parents was also assessed. The thesis concluded with recommendations for health policy makers both at federal and state level, curriculum planners, health insurance administrators and parents. Such recommendations were designed towards early diagnosis, secondary prevention rather than cure, social support programs and public health education. It sought also to identify ways to streamline access to health care, communication among doctors, doctor to patient as well as patient to patient communication.

Statement of the Problem

Autism is the fastest growing known developmental disability in the world. According to the World Health Organization (WHO, 2007), more children would be diagnosed with autism this year than cancer, diabetes, Down's Syndrome and AIDS combined. In the United States, the federal Centers for Disease Control and Prevention puts prevalence of autism at one in 150 children and the ratio of boys to girls with autism estimated at 4 to 1 (CDC, 2008). The cost burden of the national population suffering from autism is estimated at about 100 billion annually and projections for the next ten years with the current rates of diagnosis are that each autistic child in a family in the United States would require 3 to 5 million dollars of services throughout the lifetime of that child (about 200 to 400 billion dollars of annual national budget) (CDC, 2008). While the stress of raising autistic children is enormous and diverse, autism is treatable and the cost of lifelong care for autistic children can be reduced by two-thirds with early intervention, but it receives less than 5% of the research funding of most of the more prevalent childhood disorders (Hoffman, 2008).

Purpose of the Study

The specific objective of the study is to evaluate any predictive stressors at odds with parenting stress in the (path of) complain, diagnosis and prognosis continuum of autism. Next step is to identify appropriate statistical models available for a meaningful analysis and interpretations of available data with the aim to ascertain and reinforce existing risk factors, which might bring about parenting stress and frustration. Finally, it

is the aim of this study to come out with specific recommendations, which would address such factors in an attempt to mitigate parenting stress of autistic children. Such recommendations would target curriculum planners to re-evaluate medical programs and to take specific steps to equip new graduates to provide the needed help to reduce parenting stress. It is also the expectation of this project to reinforce existing information from other sources of reference for parents with autistic children on risk factors of the disease, knowledge of which would reduce anxiety and stress.

Research Questions

This study would attempt to answer the following questions.

- (1) What predictive factors contribute to stress when parenting autistic children under eighteen?
- (2) Is there any additional stressors interacting with existing test variables at odds with parenting autistic children?
- (3) Are these test variables the same for children with special care needs other than autism?

The study would examine a number of variables, in the cultural, psychological, social and economic context in order to ascertain their impact on parents as they struggle to raise their children with autism. The impact of these factors would be studied on parents, peer group and siblings in the family. Demographic data would also be considered to ascertain the stress level and distribution by age and gender of children.

The Study Hypothesis

This study would test three hypotheses at alpha level (significance) of less than 0.05. These hypotheses are as follows:

- (1) Stress associated with parenting children with autism is dependent on access to health care, knowledge of frontline or primary health care provider (PCP), availability of insurance, income limitations and social support.
- (2) Stress odds for parents with autism are higher compared to the stress levels of parents of children with other special care needs. The difference may be due to availability of coping mechanisms which may be lacking for parents of children with autism.
- (3) Severity of stress odds may be due to the age and educational level of parents, number of children in the family with autism, availability of insurance and social support, language barrier and lack of cultural sensitivity of doctors.

Delimitations

This study would be limited to data collected on children with special care needs, 2005 to 2006 with special reference to autism. Certain data may be system eliminated for privacy protection such as data for Katrina and Rita victims.

Limitations

The findings of this study may have some notable limitations such as:

- 1) The data collection was self-reported by phone. It is therefore impossible to corroborate underreporting and over reporting. Some of the respondents may either not

have home telephones or have not enlisted their telephone numbers in the phone public directory.

2) Some of the variables used provided inferred information rather than direct measurement on stress. For example, high educational background and maturity of a parent did not necessarily constitute mitigating stressor for raising a child with autism. Comparatively, loss of job due to long hours spend caring for a child culminating into loss of employer provided insurance may be seen as a direct stressor.

3) Given that respondents had to rely on memory recall providing information about past experiences raising autistic children ranging from 30 days to 12 months, may have resulted into information recall bias.

4) Finally, since the survey was administered in English, there is a possibility of a language barrier that may have set a limit to depth and accuracy of information provided.

Importance of the Study

Early diagnosis and referral to treatment has been identified in public health as the key to improve prognosis of most health problems. Even though it is critical to receive early intervention and social support services, delays of which are devastating to both children and parents, autism is often not diagnosed until the child is 3 to 4 years (Lazartigues, Planche and Lemonnier, 2004). Studies in both the United States and United Kingdom indicate that parents are able to identify symptoms of autism as early as 6 months and seek medical attention, but there is an average delay between complain and diagnosis of between 4 to 6 years (Rhoades, Scarpa and Salley, 2007). Researchers have

also found out that parents are mostly correct about the noticed symptoms. Various reasons have been assigned to the delay in diagnosis. Firstly, pediatricians and family practitioners, who are the front contact of these parents, may often not be sure on the emotional reactions of the parents knowing the chronic or the life long nature of the disease. It is also possible that the front contacts lack adequate training or are not confident to provide the needed assistance that parents look for. Sometimes, delayed diagnosis may be attributed to optimism that conditions might improve. Studies among the French society suggested that pediatricians did not believe that parents are able to read symptoms of autism correctly and often dismissed their concerns as trivial or inaccurate (Lazartigues et al, 2004). A study to ascertain the depth of knowledge among prospective doctors reveals that in a survey, 4th year medical students performed poorly on questions about causalities of autism (Shah, 2001). Furthermore, studies also suggested that 33% of physicians discussed or suggested non-clinically supported therapies for autism with parents, which may be attributed to their own lack of knowledge on the disease (Skellern, McDowell and Schluter, 2005). As a consequence of the factors discussed so far, parents in their frustration and anxiety might resort to other inaccurate and unmonitored sources like the internet for solution. These unmonitored sources may provide too much confusing and sometimes harmful information. It is the hope of this project to initiate the needed impetus that would replicate and expand the stated objectives in future research (Rhoades et al, 2007).

CHAPTER 2

REVIEW OF RELATED LITERATURE

History and Early Symptoms of Autism

The term, autism, has its origin from the Greek word “autos” meaning ‘self’ used to describe a solitary person or someone who avoids social interaction. Literally, “auto” means an isolated self. The Swiss psychiatrist, Eugene Bleuler, first applied the word to describe one group of symptoms of schizophrenia in 1911 (Hoffman, 2008). In the United States, researchers did not apply the term until 1940s, when it was used to describe children with emotional or social problems. “Leo Kanner, a doctor from Johns Hopkins University, used it to describe the withdrawn behavior of several children he studied. The term was used almost simultaneously by a German scientist, Hans Asperger, to describe similar conditions he identified now called Asperger’s syndrome” (Hoffman, 2008). However, autism and schizophrenia remained linked in many researchers’ minds until the 1960s, when medical professionals began to have a separate understanding of autism in children.

The etiology of autism is still elusive and remains an active research question in the minds of many clinicians and scientists. Most experts attribute autism to a combination of genetic and environmental factors, but have no definite answers to the specific causes. Most baffling to researchers is the fact that no two people diagnosed with autism have the same characteristics. (Rhoades et al, 2007). For many researchers, the uncertainties associated with the disease are terribly frustrating. Given the international distribution of the disease, many theories have been promulgated globally in an attempt

to explain some of the apparent causes. Generally, many clinicians believe that environmentally related prenatal factors and parental psychopathology are associated with the risk of autism and that these factors may have been acting independently. Writing on the early signs of autism, Evans (2006) advised pediatric evaluation triggers like the child's inability to do the following: smiling by six months of age, babbling, pointing or using other gestures by 12 months, using single words by age 16 months, using two word phrases by 24 months and having a regression in development, with any loss of language or social skills (Evans, 2006). Given that no two people diagnosed with autism have the same characteristic features, the suggested evaluation triggers may be inapplicable to all children.

Even though new challenges are normally associated with parenting teenagers, worse forms of challenges may evolve with maturing autistic teenagers because they have difficulty communicating with their peers and struggle to fit in; while at the same time, they often want to pull away from their parents. The resultant social isolation coupled with issues of raging hormones associated with adolescence and a limited ability to understand or appropriately manage sexual behaviors can lead to a number of complications (Evans, 2006). Living with autism may also bring added stress to the entire family. Siblings may sometimes feel the needed attention is drifting away and that their needs are either not being met or pushed to the periphery on the scale of importance compared to the needs of their brother or sister with autism. "Also, couples may find their lives revolving around the care of their child with autism and be unable to find time to be with each other. This is 'dangerous ground' and if allowed to continue can lead

breakdown of the relationship and the entire family” (Evans, 2006). In addition there is a possibility of many financial stresses resulting from limited work hours to care for children with autism. According to Evans (2006), since people with autism have a normal life expectancy, naturally, plans must be made for their adult life. Uncertainties over the future of any child with autism may therefore bring anxiety and frustration to such families (Evans, 2006).

Findings in a case control studies in London on association between family history and autism studies, using Down’s syndrome as controls suggested “that autism phenotype extends beyond autism as was traditionally diagnosed. The study emphasized that the etiology of autism involves several genes; that autism is genetically heterogeneous and that obstetric abnormalities in autistic subjects may derive from abnormality in the fetus” (Bolton, Macdonald, Pickles, Rios, Goode, Crowson, Bailey and Rutter, 2006). Researchers at the University of Washington, Autism Center (UWAC), Seattle, reinforced earlier scientific studies that autism spectrum disorder, one of the types of autism, is associated with a disproportionate rate of head growth in early childhood. The UWAC research team reported that “increased rate of growth may index aberrant processes during early development, precede the onset of symptoms, and predict trend severity of the disease” (Webb, 2007). An international consortium, “using an affected sibling pair strategy has found a promising linkage to a region on chromosome 7” According to a study conducted in department of Child Psychiatry, University Medical Centre Utrecht, (CPUMCU) in the Netherlands, 10 to 15% of cases of autism are due to associated medical conditions that affect the normal brain functioning” (Buitelaar and

Willemsen-Swinkels, 2000). This suggestion was confirmed by “postmortem studies on small case series report on cellular abnormalities in the limbic system and cerebellum. According to the study, “10 and 20% of individuals with autism have macrocephalia, which is in accordance with magnetic resonance imaging (MRI) findings of an increased total brain tissue volume and enlargement most prominent in the occipital and parietal lobes” (Buitelaar et al, 2000).

Early Diagnosis and Prognosis of Autism

As indicated earlier in the introduction of this report, autism can manifest itself in a couple of different ways. Autistic disorder is the one most people visualize when they hear the word ‘Autistic Spectrum Disorders’ (ASD). Asperger Syndrome, for example, is a highly functional form of ASD, while Childhood Disintegrative Disorder and Rett Syndrome is the form known to occur only in women. Pervasive Developmental Disorder is a form not otherwise specified (PDD-NOS, including atypical autism). For Childhood disintegrative disorders, like Rett syndrome, the child begins developing normally, until about age 2 to 10, when he begins to experience increasingly less ability to interact and communicate with others (Hoffman, 2008). The exact mechanisms behind the formation of autism are still not very well understood. Some researchers reported a more understood causes to include genetic errors, where the DNA does not replicate properly (Hoffman, 2008). Other reports suggest that families with history of autism are more likely to find autism in their children. It is also possible that a number of environmental factors can contribute to the development of autism, including the possibility of viruses and air

pollutants or toxins like mercury, lead and benzene. Immune system issues and delivery problems can be a factor in the development of autism. Keen observation, close monitoring, regular check-ups and child's or doctor's willingness to test for developmental delay may facilitate early diagnosis (Rudy, 2009). Frontline physicians may refer abnormal developmental trends in a timely fashion to a specialist, who may perform formal specialized evaluation on the children. Diagnosis is difficult due to the varied nature of the disorder. The diagnosis for autism cannot be done based on a single test, rather a diagnostic procedure of tracking the development of the child's verbal, social and behavioral skills would be ideal. Although signs of autism may develop as early as 18 months, the diagnosis may not be made until the child is at least 2 or 3 years of age. There is no cure for autism, but early diagnosis improves prognosis as intensive therapies can help to treat behavioral, social and language abilities (Rudy, 2009). Some medications can help with issues, such as anxiety and other severe behavioral problems. Highly structured educational programs can also contribute to boosting the social, behavioral and lingual abilities of the child (Hoffman, 2008).

Communication and Knowledge of Primary Health Physicians

Communication is considered one of the most important prerequisites for quality health care. Studies have clearly demonstrated that lack of language proficiency is associated with poor access to preventive and health care services. Language barriers and cultural barriers also contribute to accessibility of care as well as difficulties in obtaining adequate histories on morbidity, communicating medical advice and health promotion

information, inability to book appointments, follow advice on prescriptions, patient satisfaction, poor overall outcomes and quality of care (Pottie, 2007)

In spite of the many adverse effects of communication on health care highlighted above, statistics indicate that many patients who need medical interpretation have no access to interpreters. Writing on Language Barriers to Health Care in the United States, published in the *New England Journal of Medicine* (NEJM), Flores (2006) stated that “no interpreter was used in 46 percent of emergency department cases involving patients with limited English proficiency. Few clinicians receive training in working with interpreters; only 23 percent of U.S. teaching hospitals provide any such training, and most of these make it optional. Data collection on patients' primary language and English proficiency is frequently inadequate or nonexistent. Although no federal statutes require the collection of such information, no statute prohibits it, either” (Flores, 2006). Meanwhile, influx of undocumented immigrants to the US is continuous and complicates the associated health implications. According to one study reported in the NEJM (2006), language barriers can have deleterious effects. Flores (2006) explained that patients who face such barriers are less likely than others to have a regular source of medical care; they receive a discounted cost of preventive services yet they have increased risk of non-adherence to medication. “Among patients with ASD, those who encounter language barriers are more likely than others to receive late diagnosis, severe psychopathology or depression yet they are also more likely to leave the hospital against medical advice”. They are also less likely than others to return for follow-up appointments after visits to the emergency room for fear of deportation. They have higher rates of hospitalization and drug complications. “Even

though greater resources are used in caring for such patients, they have lower levels of patient satisfaction” (Flores, 2006).

Similar to findings in the US, a study in the United Kingdom reported that the average age of diagnosis of a child with ASD was six years, even though most families felt that something was wrong with their child at 18 months and sought medical attention at age 2 (Rhoades et al, 2007). “Others have found the average delay between when a parent first seeks help and the time of diagnosis to be four years. It has been suggested that parents are often correct about concerns with their children's development, and symptoms of autism can frequently be seen before 12 months of age” (Rhoades et al, 2007). Investigators have established lack of knowledge of doctors as a major draw-back in the diagnosis-treatment-prognosis of Autism Spectrum Disorder (ASD). Consequently, parents in their frustration and anxiety might resort to other inaccurate and unmonitored sources like the internet for solution. These unmonitored sources may provide too much confusing and sometimes harmful information. It is the hope of this study to initiate the needed impetus that would replicate and expand the stated objectives for future research not only in the United States, but elsewhere especially in the developing countries.

Access to Insurance

Given that treatments for autism are difficult to access, often inadequate, and frequently delayed, coverage is likely to be less attractive to private health insurance companies. Empirical evidence suggests that from a purely business perspective, where coverage is made available, it is likely to be very expensive leaving parents with no

option, but to either pay out-of-pocket or forego the treatments for their children altogether. Parents may get coverage from employers, but in a situation where home care for autistic children is so demanding that some parents often cut down work hours or quit working completely, this option might remain a hallucination or unattainable (Ganz, 2007).

The 2001 U.S. Surgeon General's Report on Mental Health states: "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior" (Autism Speaks, 2007). In spite of this officially recommended approach to tackle autism, there is no national health insurance policy in place to compel insurance companies to include coverage plans for autism services. Families have difficult time accessing the necessary treatments through Medicaid and private health insurance and most insurance policies contain specific exclusions for autism services. "This is a hardship for many families, who are often forced to cope with delayed, inadequate, and fragmented care through the Medicaid system. Often, families must pay for costly treatments out-of pocket or forego them" (Ganz, 2007).

Children with autism often experience barriers to health care 'access' with even greater frequency than children with other special health care needs. According to one study "over one-third of the children with autism were reported to have experienced an access problem with respect to specialty care from a medical doctor in the preceding 12

months” (Krauss, Gulley, Sciegaj, and Wells, 2003). Institute of Medicine, defined ‘access’ as: “the timely use of personal health services to achieve the best possible health outcomes” (Millman, 1993). Another study conducted on the Tennessee Medicaid system, TennCare, reported that for children with autism, “the rate of service use was only one tenth what should be expected based on prevalence rates. Within the Medicaid system, the amount of public money spent on services for developmental disabilities including autism is now eight times the rate of spending just a few decades ago” (Mandel, Cao, Ittenbach and Pinto-Martin, 2006). Medicaid accounts for 75% of all funding for services for the developmentally disabled, making it the largest single public payer of behavioral health services (Ruble, Heflinger, Renfrew and Saunders, 2005). Children with disabilities comprise a significant portion (15%) of all Medicaid recipients, and an even more significant portion (31%) of disabled children use the Medicaid system as their primary insurer (Millman, 1993).

Socio-Economic Impact of Autism on Households

From the psycho-social evaluation of families, theory has it that parents of children with Autistic Spectrum Disorders (ASDs) are more likely to experience serious psychological distress than parents of children with other developmental disabilities. To examine the impact of a range of factors on psychological wellbeing parents, researchers in Manchester, UK interviewed 68 mothers of children with ASDs to explore aspects of social support, mental health status and satisfaction with health care services. Findings indicated that over half of mothers screened positive for significant psychological distress

was found to be associated with low levels of family support and bringing up a child with higher levels of challenging behavior. Findings from the same study also reveal that “mothers were more likely to report lower levels of support, if they were single parents, were living in poor housing, or were the mother of a boy with ASD. The study also investigated areas of useful support and areas of unmet need, the latter including care breaks and advice needs” (Bromley, Hare, Davison and Emerson, 2004). Research has also shown that households that have children with disabilities are at risk of experiencing significantly lowered incomes due to lesser work hours or higher premium on private insurance (Porterfield, Sanders and Rainford, 2006). A research conducted on the wealth and asset holdings of married-couple households with children, reported that households having children with disabilities are “less likely to own a house and to own interest-bearing assets, though the values of these assets, if held, don't vary with the disability status of children. The presence of a child with disabilities does not affect the number of automobiles owned, but does significantly reduce the average value of each vehicle” (Porterfield et al, 2006).

Government Policies and Support Programs

As stated earlier, in many states, insurers in the US explicitly exclude coverage of ABA and autism related therapies from their policies, which places a significant financial burden on families seeking to provide their children with necessary services. However, four of the states, South Carolina, Texas, Indiana and Arizona have passed autism insurance legislation as quoted below: “South Carolina Senate Bill 20, better known as

Ryan's Law, was passed by both the House of Representatives and Senate on May 31, 2007. The bill was then vetoed by Governor Mark Sanford on June 6. On June 7, the bill was brought back to the House and Senate floors, and unanimous votes in both chambers overrode the Governor's veto". This law went into effect in July 2008 (SARRC, 2008 / S.C. 2007). The law mandated treatments, including behavioral therapies like ABA, which are prescribed by the individual's treating medical doctor in accordance with a treatment plan; stipulated that individual must be diagnosed with autistic spectrum disorder at age eight or younger; that coverage must be provided to any eligible person less than sixteen years of age and that the cap dollar coverage for behavioral therapy is subject to a \$50,000 maximum benefit per year (SARRC, 2008 / S.C. 2007).

“On June 15, 2007, Texas enacted House Bill 1919, effective September 1, 2007. While the Texas bill limits the ages for children who can benefit from coverage, it goes further than some other states in spelling out exactly what kinds of services are covered. The bill's text specifically cites which kinds of autism-related services are examples of treatments that must be covered. Coverage includes evaluation and assessment services, ABA, behavior training and behavior management, speech therapy, occupational therapy, physical therapy, medication or nutritional supplements used to address symptoms of ASD. Age range at which an individual must be diagnosed should be between ages three and five to receive this coverage, while the cap dollar remains the same as afforded to physical illnesses” (SARRC, 2008 / Tex. 2007).

“In 2001, the state of Indiana enacted House Bill 1122, requiring insurers to issue accident and sickness insurance policies on an individual basis to provide coverage for the treatment of ASD. Coverage includes treatment that is prescribed by the insured’s treating physician in accordance with a treatment plan. The statute thus allows many different professionally accepted therapies, such as ABA, speech therapy, occupational therapy, physical therapy, and medications to address symptoms of autism. All ages are allowed coverage while dollar cap remains the same as afforded to physical illnesses” (SARRC, 2008 / Ind. 2001).

Given the progress made in dealing with autism in the three states mentioned above, other states like the state of Arizona try to follow with similar legislation. “Arizona House Bill 2847 just passed in March 2008. The Governor, Janet Napolitano and the state's legislators enacted House Bill 2847, which would require insurance carriers to provide coverage of evidence-based, medically necessary autism therapies. The new Arizona law requires insurers to cover up to \$50,000 a year for ABA therapy for children until they turn nine, and \$25,000 a year for children until age sixteen. It covers therapy for children whose diagnoses reflect the full range of the autism spectrum. As stated earlier, ABA is recognized by the American Academy of Pediatrics (AAP) and the U.S. Surgeon General (SG), among others, as an effective, evidence-based treatment for children with autism” (SARRC, 2008).

At the federal level, on Dec. 19, 2006, the president signed the Combating Autism Act (S.843) into law. This historic piece of legislation authorized nearly \$1 billion over the next five years for the National Institutes of Health to conduct autism research,

surveillance, education, early detection and intervention. In spite of this federal legislative achievement, it must be stated that given the incident rate of one in one hundred and fifty, the federal response to combat autism is rather disappointing. Existing federal policy regarding the need for supports and services for children with ASD are fragmented inconsistent and require a legal framework to operate efficiently.

CHAPTER 3

SCOPE, DATA AND METHODOLOGY

Source and Scope

The scope of this data is solely limited to The National Survey of Children with Special Health Care Needs (NS-CSHCN). This particular survey, 2005 – 2006, was sponsored and funded by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA); conducted by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS). The survey sampling structure used for this study was also provided by CDC's National Center for Immunization and Respiratory Diseases (NCIRD). The National Operations Research Center (NORC) at the University of Chicago and its subcontractors conducted all interviews for this project. This report was edited by personnel of CDC's Division of Creative Services. The report's outline and some texts were fashioned in the same manner as the earlier version of the NS-CSHCN conducted in 2001, use of which was permitted by Vital and Health Statistics Design and Operations. Both the 2001 and 2005–06 of NS-CSHCN were conducted as part of the State and Local Area Integrated Telephone Survey (SLAITS) program developed under Title V of the Social Security Act. This is a federal versus state ongoing partnership program, whose primary objective is to assist states to provide a coordinated system of health care for CSHCN (Blumberg, Welch, Chowdhury, Upchurch, Parker, and Skalland, 2007).

Data and Data Collection

No primary data was collected for this thesis. The publicly available secondary data used was down-loaded from NS-CSHCN website (<http://www.cdc.gov/nchs/slaits/cshcn.htm>). This secondary data collection was by Random-Digit-Dial (RDD) sample and Computer-Assisted Telephone Interview (CATI) technology, results of which were presented in four SAS files among others: Screener, Interview, Household and Referent each contain a list of variables. Each variable comprises a set of questionnaire(s). This is also publicly available at index of [ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/slaits_cshcn_survey/2005_2006/SAS Variable Format Files/](ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/slaits_cshcn_survey/2005_2006/SAS_Variable_Format_Files/). The interview process was separated into two stages: the first interview was aimed to identify children between ages 0 and 17 years from whom general health information was extracted. The second interview was performed on those who were identified as CSHCN to obtain more specific health related information. The data collected for this preliminary identification of age group is classified as ‘CSHCN Screener’. Oregon Health and Science University administered the five stem questions on general health needs out of which chronic health conditions lasting 12 months or longer were identified as special needs for follow-up interview. For methodological purposes, the second interview was sub-divided into two, ‘main’ and ‘referent’ samples. The main files are three in all: CSHCN_Main_Household.sas, CSHCN_Main_Interview.sas, and CSHCN_Main_Screener.sas. CSHCN_Referent.sas, the national referent sample was on children without special health care needs (SHCN) and the state based main sample on children with SHCN. Objectives for this approach were twofold:

- (1) To produce national and regional estimates on children without SHCN in order to evaluate the differences for comparison between children with and without SHCN; and
- (2) To produce national and regional estimates of the prevalence of CSHCN with a different screening technique.

All together 56,014 were identified to have special health care needs residing in 44,923 screened households. For the purposes of this project variables used for this analysis were obtained from the combination of three files. Consequently, all respondents used for the analysis were drawn from the following files of sample population: (a) INTERVIEW, (b) SCREENER and (c) HOUSEHOLD. In all the total sample size extracted from the CSHCN, 2005-2006 used for the analysis was 40,723. This number comprised of 2123 respondents with autism, 38,133 respondents without autism and 467 missing values. The focus for the analysis was on looking for stress indicating variables likely to be found among parents of children with autism in relationship to those stress indicators found among parents of children without autism.

Protection of Human Subjects

Participation in surveys conducted by NCHS is voluntary, and all individually identifiable information collected is confidential. For the National Survey of CSHCN, assurance of confidentiality was provided to potential respondents as part of the informed consent procedures. The National Center for Health Statistics (NCHS), Research Ethics Review Board and the National Operation Research Center Institutional Review Board (NORCIRB) based in Chicago approved all study procedures and modifications. The

federal Office of Management and Budget (OMB) control number for this NS-CSHCN, 2005-2006 collection of information was 0920-0406 (Blumberg et al, 2007). In addition, since data for CSHCN from the referent sample served methodological purposes only, it was not publicly released. However, the data file may be made available upon request. None of these data has any personal information like names or household descriptions. Additional interview questionnaires to identify affected Hurricane Katrina in August and Rita in September evacuees were also excluded from the public domain for privacy and protection of human subjects. Even though the hurricane affected states were Florida, Louisiana, Mississippi, Alabama, Tennessee, Texas, and Arkansas, the additional questionnaires were administered to all 50 states and District of Columbia in January 2006 (Blumberg et al, 2007). By mixing up the peculiar information from the hurricane victims with those which were not affected, it is virtually impossible to distinguish any household family from the fifty states jumbled together and presented only as files.

Methodology

All data analyses were carried out using the version 9.1.3 of the SAS software and all results were analyzed at less than 5% level of significance. First, all three data files, (a) INTERVIEW, (b) SCREENER and (c) HOUSEHOLD were downloaded, merged and sorted by two uniquely assigned identification numbers that came with the original data sets: files 'a' and 'b' sorted by IDNUMXR, while file 'c' was sorted by IDNUMR. Using PROC SQL command, the two identification numbers were combined into one unified identification number and recognized as IDNUMXR.

To examine the counts of the respondents' participating in the survey, descriptive statistics were constructed using the (PROC FREQ) SAS frequency command tool. This command displayed the sample size for each of the variables separately, an information vital for comparison between the variables to determine their importance and impact. Secondly, a separate descriptive analysis was constructed to determine the missing values for each of the variables. Variables with high percentage of missing values were examined very closely, most of which were eliminated based on their high percentages when constructing the model for the final analysis. This was necessary for the results to be a true representation of the population sampled. Next, the following variables were considered as stress indicators based on empirical evidence and the literature reviewed from multiple sources (Evans, 2006; Glenn, 2006 and Autism Speaks, 2007): financial problems (C9Q05), reduced working hours (C9Q06), need for additional income (C9Q07), and stopped working (C9Q10). These stress indicating variables were selected and replaced with a new variable called parenting stress (STRESS), to be defined below (Selection of Variables), which became the dependent variable. This dependent variable was measured against independent variables as listed in chapter 4 below, under the sub-headings "selection of variables" and "statistical model".

To ascertain the odds between the selected predictive variables mentioned above and parenting stress, (PROC SURVEY LOGISTIC) command was used to run the univariate logistic regression analysis for each of the variables in the model. By this method, the significance of the contribution of each variable to parenting stress would be demonstrated. The decision to use multiple logistic regression analysis was made in order

to obtain the magnitude of the contribution of each variable to stress and graded using 95% confidence interval as the precision measure. Demographic data such as age and sex was also used to ascertain which age and sex of children with autism are most susceptible to stress odds of parenting. In all analysis for this project, the stress odds of parenting a child with autism was measured relative to the stress odds of parenting children with other special health care needs other than autism.

CHAPTER 4

SELECTION OF VARIABLES, AND STATISTICAL MODEL

As a result of the limited resources and scope of this thesis, the necessary instruments could not be made available to measure parenting stress quantitatively. Parenting stress was therefore defined in terms of stress indicators such as: incurred financial problems due to child's health, involuntary reduction in work hours due to child's health, lack of additional income for child's medical expenses and cessation of work due to child's health or to devote more hours to care for a child.

Dependent Variables

The four variables that were considered to represent stress are C9Q05, C9Q06, C9Q07 and C9Q10 respectively as stated in the above paragraph and defined in table 1 below. Parents who gave at least one affirmative answer to the questionnaires associated with these variables were populated into one common variable called STRESS. For example, in connection with C9Q05 variable, parents selected for the interview were asked: "If your child had special health care needs (autism), and had health conditions that caused financial problems for your family". That is, a choice had to be made from the possible responses available to this particular question, which was: YES, NO, DON'T KNOW, REFUSED or NO RESPONSE. If all components of stress had a "NO" response, then the parent was classified as not stressed. Questionnaires with affirmative answers on similar stress defining variables are outlined in Appendix 'A' below.

Independent Variables

In all, seventeen variables were selected from the pool of variables based on the literature reviewed (Evans, 2006; Glenn, 2006 and Autism Speaks, 2007) to be major contributors to stress. These variables were selected to be analyzed with the newly constituted dependent variable (STRESS) and to ascertain any interactions between the given variables and STRESS. Independent variables include: autism status of target child (S3Q18); age of target child in years at interview (AGEC); sex or gender of target child at time of interview (SEX); race of target child (NRACER); primary language spoken in household (C2Q05R); highest educational level of anyone in the target household at the time of interview (EDUCR); health insurance status of target child during the twelve months prior to time of interview (UNINS_YR); need for routine preventive care last twelve months prior to time of interview (C4Q05_X01); need for prescription medication last twelve months prior to time of interview (C4Q05_X04); need for physical, occupational or speech therapy last twelve months prior to time of interview (C4Q05_X05); need for home health care last twelve months prior to time of interview (C4Q05_X08); need for other medical supplies last twelve months prior to time of interview (C4Q05_X13); need for respite care last twelve months prior to time of interview (C4Q06_X01); genetic problems of target child that required genetic counseling last twelve months prior to time of interview (C4Q06_X02); respondent's satisfaction with child's health services (C6Q0C); status of providers sensitive to family's values and customs (C6Q04); and communication status that required interview to be conducted in languages other than English (OTH_LANGR).

Statistical Model

Dependent variable (parenting stress) was assessed from questionnaires on the following variables: caused financial problems (C9Q05), family members have to cut their working hours (C9Q06), stopped working (C9Q10), and needed additional income for child (C9Q07). If response for any of the above categories of questionnaires was “No”, then the variable constitutes parenting stress and was categorized as “0”.

Otherwise, if response was “Yes” for all four components of stress, then stress was categorized as “1”. The literature reviewed (Evans, 2006; Glenn, 2006 and Autism Speaks, 2007) gave evidence for following variables to be considered as independent variables: preventive care (C4Q05_X01), prescription medications (C4Q05_X04), speech therapy (C4Q05_X05), home health care (C4Q05_X08), medical supplies (C4Q05_X13), respite care (C4Q06_X01), genetic counseling (C4Q06_X02), satisfaction with services (C6Q0C), providers sensitivity to family’s values and customs (C6Q04), child’s insurance status (UNINS_YR), age (AGEC), sex (SEX), race and Hispanic (NRACER), language spoken in household (C2Q05R), other languages in which interview was conducted (OTH_LANGR), educational level of parent (EDUCR).

It is worth noting that for the purposes of these analyses the two variables, RACER and HISPANIC, which were formatted as separate variables in the original NS-CSHCN data, were combined into one single variable, reformatted and named NRACER. This was done to boost the numerical strength for the respondent data on the race variable as a measure to forestall any unforeseen sample size limitations of the data. In addition, respondents’ insurance status was also modified from the original formatting. For the

purposes of simplifying the outcome and also make results and interpretations more meaningful, all the fragmented insurance statuses such as: insured for less than 3 months, 3 to 6 months, 6 to 9 months, more than 9 months but less than 12 months and 12 months (1 year) or more were all regrouped into two, insured for 12 months or more prior to time of interview or uninsured at some point during the 12 months period before the time of interview. This regrouping made it possible to assess insurance statuses of respondents as a binary (Yes/No) response variable instead of multiple responses variable.

CHAPTER 5

DATA ANALYSIS, RESULTS AND INTERPRETATIONS

Crude Odds Ratio Analysis

The single binary logit dependent or response variable for the analysis is stress or no stress association with parenting autistic children. Fisher's optimization technique was used to predict the odds of stress. In all 40,723 observations were read, but 40,256 were used leaving out 467 as missing records. For reasons explained earlier under the heading "Protection of Human Subjects", some of these missing data was either removed on purpose or respondents did not give answers to the questionnaires. The Chi-square test was done with a p-value of less than 0.0001, shows that the model as a whole fits significantly better than would have done with the model with no predictors. The odds ratio estimates showed that parents who have children with autism (S3Q18) were 4.65 times more likely to feel stressed than parents who have children without autism (OR = 4.65; 95% CI: 4.00, 5.41; p-value < 0.0001).

Parenting autistic children of all ages (AGEC) was significant with p-value for all ages at 0.016. Results showed that the younger the child, the more likely to feel stressed when parenting them. From the odds ratio estimates, parents who have younger children (0-5 years old) with autism were significantly 15% more likely to feel stressed than those who have relatively older children (12-17 years old) with autism (OR = 1.15, 95% CI: 1.04, 1.26). On the other hand, parenting stress for children (6-11 years) compared to children (12-17 years) was not significantly different (OR = 1.05, 95% CI: 0.96, 1.15).

Generally, the association between stress and race was significant among all races (NRACER) with a p-value of < 0.0001 . Using White as the reference group, the odds of parents with an African American child having parenting stress was about 21% (OR = 1.21, 95% CI: 1.09, 1.34) times greater than that of a parent of a White child. For parents of Hispanics children compared to parents of White children, the odds of feeling stressed were about 53% (OR = 1.53, 95% CI: 1.36, 1.72) higher; and the odds of feeling stressed for parents of children of other races compared to the parents of White children were about 21% (OR = 1.21, 95% CI: 1.06, 1.40) greater. (RACER and HISPANIC combined as NRACER as explained earlier).

Results of this thesis showed that language plays a very significant role in the prevalence of parenting stress among children (p-value < 0.0001). By comparison, the odds of having parenting stress among Spanish speaking parents (C2Q05R) of children were more than two times higher than that of parents who can speak English (OR = 2.09, 95% CI = 1.73, 2.52). Results of the analysis also showed that respondents with autistic children, whose primary language was not English and whose communication skills were such that interview questionnaires had to be administered in a different language other than English (OTH_LANGR), experienced very significant stress odds with a p-value of < 0.0001 . Point estimates showed 2.16 times more stress odds compared to those who had interview questionnaires administered in English (OR = 2.16, 95% CI: 1.75, 2.66). Communication plays significant role especially in the diagnosis, understanding and adherence to therapeutic instructions. Contrary to empirical evidence suggesting that the level of education of parents impacts the stress odds for parents, findings from this thesis

indicated differences between the three different levels of education for parents that have children with autism compared. Parenting stress is significant among all parents regardless of their level of education (p-value < 0.0001). Using more than high school as the reference group, the odds ratios were: parents with high school education were 26% more likely to feel stressed (OR = 1.26, 95% CI: 1.16, 1.38); and those parents who had less than high school education were 55% more likely to feel stressed (OR = 1.55, 95% CI: 1.33, 1.80).

Health insurance status showed overall significance with p-value of < 0.0001. The odds of parenting stress among the insured all through the year (UNINS_YR) were 65% less than those who were uninsured at some point in the year (OR = 0.35; 95% CI: 0.31, 0.39). Odds ratio showed no association of stress between those parents with and without access to prescription medicine (p-value = 0.46). Whether the children needed routine preventive care also showed no significant difference in association with parenting stress (p-value = 0.28). Naturally, results in this thesis showed that parents whose children needed some form of therapy had higher odds of parenting stress than those who did not need any form of therapy. Parents, who needed physical, occupational or speech therapy (C4Q05_X05), had significantly higher odds (three times) of parenting stress than those who did not need it (p-value < 0.0001; OR = 2.88; 95% CI: 2.65, 3.12). Similarly, home health care (C4Q05_X08) also played a significant role in parenting stress with a p-value of < 0.0001. Parents, whose child needed any home health care, had an even more significantly higher odds (four times) of parenting stress than those who did not need it (OR = 4.00; 95% CI: 3.35, 4.76). Parents whose children needed medical supplies

(C4Q05_X13) revealed similar significantly higher (two times) odds of parenting stress for those parents, whose children needed any medical supplies than those who did not (p-value < 0.0001; OR = 2.22; 95% CI: 2.04, 2.42).

Respite care (C4Q06_X01), home help from a family member or hired professional provides the needed social support necessary to reduce parenting stress for children with special health care needs in general and children with autism in particular. However, findings from the analysis showed that parents, whose children needed respite care, were over seven times more likely to have parenting stress than those parents whose children did not need one (p-value < 0.0001; OR = 7.30; 95% CI: 5.89, 9.06). Similarly, parents whose children needed genetic counseling (C4Q06_X02) also were three and half times more likely to have parenting stress compared to those who did not need any genetic counseling (p-value < 0.0001; OR = 3.62; 95% CI: 3.06, 4.28).

Logically speaking, satisfaction with child's health care services (C6Q0C) should form the basis of confidence and the general desire for parents to seek medical help from health care providers. It follows that lack of satisfaction would reduce patronage of child's health care services even though parents needed such services for their children health problems, which therefore resulted into increased odds of parenting stress among parents of autistic children. Findings from this thesis reveal significant protection from parenting stress for respondents of children with autism, who were satisfied with child's health care services they received (p-value < 0.0001). Using the very dissatisfied group of parents as the reference group, the very satisfied parents have 80% less likely to have parenting stress compared to the very dissatisfied parents (OR = 0.20; 95% CI: 0.16,

0.25). Similarly, the somewhat satisfied parents of children with autism have 55% less likely to have parenting stress compared to the very dissatisfied parents (OR = 0.45; 95% CI: 0.37, 0.56).

An analysis of effect shows a significant impact of providers' sensitivity to family's values and customs (C6Q04) on parenting stress (p-value < 0.0001). Odds ratio estimates by comparison using parents with providers, who are never sensitive to their family's values and customs as reference, the 'always group' parents experienced 64% less odds of parenting stress (OR = 0.356; 95% CI: 0.28, 0.45); the 'usually group' parents experienced 39% less odds of parenting stress (OR = 0.61; 95% CI: 0.48, 0.78); the 'Sometimes group' did not show significant difference in odds of parenting stress (OR = 0.94; 95% CI: 0.73, 1.23).

Test for Interactions of Variables

To a large extent, diagnosis prognosis and cure in health care is dependent on communication between doctors and patients; among doctors and among patients. Adjusted odds ratio analysis for this thesis indicated significant correlation between autism and primary language spoken in the household of respondents. P-value of 0.0213 was reported for the correlation between autism and primary language. Interaction between autism and prescription medication supplies also show significant correlation with p-value of 0.0115. Finally, analysis of this sample population indicated significant interaction between autism and the following two stress indicating care service variables with p-values of 0.0068 and 0.0123 respectively: home health care services and genetic

counseling services. As a result of the presence of interactions between autism variable and 4 other indicators, data was stratified by whether the children have autism. Multiple logistic regressions were performed and adjusted odds ratio was obtained.

Adjusted Odds Ratio Analysis

In all, out of the seventeen selected stress measuring parameters used in the model, the adjusted odds ratios show that nine of these independent variables are statistically significant among the population of children with autism. However, among the respondents without autism, eleven of these stress indicating variables were significant. The first and most important of these variables was *primary language* spoken in the household, which was found to be a significant stress indicator among *both stratifications*. Among the sample population of *children with autism*, analysis showed a statistical significance with p-value of 0.0027. In this same group results also showed a greater margin of odds ratios association with stress (AOR = 9.44, 95% CI: 2.18, 40.96) at among Spanish speaking respondents than English speaking respondents with a wider confidence interval. Even though this same variable had similar significant level with p-value of 0.0087 among the sample population *children without autism*, odds ratios were by far a lesser margin of 1.61times more stress among the Spanish speaking (AOR = 1.61, 95% CI: 1.13, 2.30), the strength of association of stress among the population of children without autism was not as sharp a contrast as it was among the sample population of children with autism.

Interview questionnaires administered in *other languages* did not showed significance in both stratifications (p-value=0.27 in ‘Yes’ strata, and p-value=0.7555 in ‘No’ strata). *Education and home health care* were significant among the study population *without autism only*. Using more than high school parents level of education as the reference with over all p-value of less than 0.0001, the association of stress found parents with high school education among this group of respondents without autism was 1.27 times more in terms of odds (AOR = 1.27, 95% CI: 1.13, 1.42), while respondents with less than high school education had 1.36 times greater stress odds than the reference group (AOR = 1.36, 95% CI: 1.10, 1.68). Home health care among respondents without autism, was also significant with p-values of less than 0.0001 for the study population of CSHCN for 2005-2006 living in the United States. Parents, whose children needed home health care had indications of stress about two times more odds than parents, whose children did not need home health care (AOR = 1.98, 95% CI: 1.57, 2.50).

Stress among respondents, who were “continually insured throughout the year of interest” was also significant among the *two stratified populations*. Respondents with autism had p-values at 0.0160 while adjusted odds ratio indicated 66% less odds of stress for the insured group throughout the year compared to the uninsured at some point of the year (AOR = 0.34, 95% CI: 0.14, 0.82). For respondents without autism, stress associated with insurance status was even more significant between the insured and the uninsured with p-values at less than 0.0001. The odds ratio estimate pertaining to insurance status was similar between the autistic and non-autistic. The benefits of having constant supply of prescription medication as stress indicating variable was also significant among *both*

stratified respondents. Comparatively, however, the levels of significance are more among parents of children with autism than parents of children without autism. Parents of children with autism reported an overall p-value of 0.0006. For those who reported their children needed prescription medication, there was a 2.07 times higher odds of feeling stressed compared to those whose children did not need prescription medication (AOR = 2.07, 95% CI: 1.36, 3.14). P-value of needing prescription medication for respondent population without autism was significantly at 0.0325. There was 1.17 times more likelihood of parenting stress in parents whose children needed prescription medication compared to those whose children did not need it (AOR = 1.17, 95% CI: 1.01, 1.36). Similar results were found with needing medical supplies (like bandages, cotton, alcohol, etc.). After adjusting other variables, p-value for significant needing medical supplies among autistic children was 0.0367. Odds ratio showed 84% higher odd of parenting stress for those whose children needed medical supplies compared to those did not need it (AOR = 1.84, 95% CI: 1.04, 3.27). Among the study population without autism whether they needed medical supplies or not, an overall p-value of less than 0.0001 was reported with indications of significant difference between groups. Parents whose children needed medical supplies were two times more likely to feel stressed compared to those whose children did not need them. (AOR = 1.99, 95% CI: 1.79, 2.22).

Given the nature of children with special health care needs, certain categories of care services were reported to have had significant impact on odds of stress among *both stratified respondents*. Such care services were: physical, occupational or speech therapy, respite care and genetic counseling. Among parents of children with autism, a significant

p-value of 0.0031 was reported for the effect of needing therapies. There were 83% more odds of parenting stress among parents whose children need either *physical, occupational or speech therapy* compared to those who did not need such care services (AOR = 1.83, 95% CI: 1.23, 2.74). Respondents without autistic children also reported significant effect of needing therapies with p-value less than 0.0001. Odds ratios indicated that parents whose children needed either physical, occupational or speech therapy had 1.92 times of stress odds compared to those respondents whose children did not need such care services (OR = 1.92, 95% CI: 1.73, 2.15). With regards to *respite care services*, both stratified groups of parents of children with and without autism had the same very low p-values of less than 0.0001. Similar values of odds ratios was also reported: While parents of children with autism had indicators of stress at 3.71 times (OR = 3.71, 95% CI: 2.18, 6.30), parents of children without autism had 3.17 times (OR = 3.17, 95% CI: 2.40, 4.19) more odds for those who needed respite care services compared to those who did not need such services. Similar low p-value, < 0.0001, was reported for the impact of *genetic counseling services* on odds of parenting stress for only parents without autistic children while the effect for the other stratification was not significant (p-value = 0.7797). The odds of being stressed for parents whose children need any genetic counseling services among the non-autism group was 2.14 times higher than those who did not need such services (AOR = 2.14, 95% CI: 1.73, 2.66).

From empirical perspectives, levels of satisfaction derived from health care services should be inversely proportional to the odds of stress. The impact of *parents' satisfaction with child health services* on parenting stress has significant impact on *both*

the groups of parents with autism and without autism. P-values for the two stratified groups were less than 0.0001. Given a reference group as very dissatisfied, parents of children with autism, who were somewhat dissatisfied (AOR = 0.96, 95% CI: 0.39, 2.36) and somewhat satisfied (AOR = 0.59, 95% CI: 0.26, 1.37) reported no significant difference but the very satisfied respondents reported 73% less odds of feeling stressed (AOR = 0.27, 95% CI: 0.11, 0.65). Among parents of children without autism, using the same reference group, the somewhat dissatisfied parents showed no significant difference (AOR = 1.02, 95% CI: 0.75, 1.39), while the somewhat satisfied had 53% less odds of feeling stressed (AOR: 0.47, 95% CI: 0.36, 0.60) and the very satisfied had 74% less odds of feeling stressed (AOR = 0.26, 95% CI: 0.20, 0.33).

Finally, health care providers' sensitivity to respondents' family values and customs was also found to be a very significant indicator of parenting stress. Significantly low p-values of 0.0295 and less than 0.0001 were reported for the group with autistic children and the group without autistic children respectively. With the providers never sensitive to family values and customs as the reference group, among parents of children with autism, adjusted odds ratios assessment indicated no significant difference for providers' always sensitive to family values and customs (AOR = 1.68, 95% CI: 0.72, 3.90), while the sometimes and usually are 2.56 times more likely to feel stressed (AOR = 2.56, 95% CI: 1.01, 6.48) and 2.79 times more likely to feel stressed (AOR = 2.79, 95% CI: 1.17, 6.64) respectively. Among parents of children without autism, the always group had 27% less odds of parenting stress compared to the never group (AOR = 0.73, 95% CI: 0.53, 0.99).

CHAPTER 6

DISCUSSIONS AND CONCLUSIONS

Parenting children with autism is indeed a daunting task as confirmed by the many significant stress indicating factors. From the analysis presented from this sample population it can certainly be deduced that parenting children with autism presents many developmental, psychological and physical challenges, which require numerous care therapeutic services from several different disciplines. It is also clear from the analysis that management of these services places financial and manpower burden on families. As indicated in the most of the literature reviewed and confirmed from the findings of this thesis, the need to remodel the current specialist provider-child interactive treatment approach to a more holistic collaborative family centered approach is currently gaining momentum both nationally and internationally (Evans, 2006; Schieve, Blumberg, Rice, Visser and Boyle, 2007; and The Global and Regional Autism Spectrum Partnership, 2008). Based on empirical evidence, skeptics may argue that parenting children with autism comes with the same challenges as parenting children with other developmental needs and therefore outcome of stress odds for these two counterfactual populations would yield no meaningful differential results. However, the outcome of this thesis has proved that the old adage that says “the devil you know is better than the angel you don’t know” still applies in our daily life experiences. Even though the difficulties of parenting a child with autism might be similar to those of parenting children with other developmental disorders, given that parents of children with other developmental

disorders are already fully aware of the physical, mental, psychological and social developmental challenges and the available coping mechanisms, the stress odds of these parents is likely to be extensively mitigated. For example, findings from this analysis illustrated that even though primary language as stress indicating variable is significant among both stratified groups of respondents (with and without children with autism), the adjusted odds ratios for parents of children with autism was 9.44 times compared to 1.61 times among parents of children without autism. It follows that the intensity of language as stress indicator is about nine times more stress burden for parents with autistic children than for parents without autistic children. From this illustration, it can be concluded that language is a major barrier to parenting children with autism and has more stress odds than parenting children with other developmental needs.

Given the above limitation, stress comparisons analysis could not also be carried out to answer the third study question: Are these test variables the same for children with special care needs other than autism?

Parents of children with autism faced with unfamiliar challenges with no ready solutions unlike the parents with other special health care needs other than autism who are mostly well educated on established coping mechanisms. Results of this thesis also show that education has significant impact on parenting stress for children without autism only. The analogy here is the higher the education level of parents of children without autism the better they are able to cope, when faced with new parenting challenges associated with children without autism. By contrast, since autism is a relatively new disease and coping mechanisms are non-existent, higher levels of education for parents of

children with autism would not make any significant impact on parenting stress. Findings of this thesis also points to barriers between provider and parents relating to provider-patient relationships, culminating into increased odds of stress. For example, results of the analysis indicated that both parents of children with autism and without autism experience significant odds of stress resulting from lack of sensitivity of provider to family values and customs with p-values of both less than 0.05. Insurance also limits access to health care for both stratified groups of parents. Significant odds of stress were reported among respondents, who had did not have constant access to insurance throughout the year of interest

Another confirmation of the positive correlation between availability of coping mechanisms and parenting odds of stress can be seen among respondents whose children needed prescription medication and other medical supplies. Parents, whose children needed prescription medication, and other medical supplies among respondents of both children with and without autism, reported more parenting odds of stress than those whose children did not need supplies. Similarly, availability of other care services at home to augment those services at provider's office mitigates odds of parenting stress for parents of children without autism. Again, given that autism is still relatively new without many coping mechanisms; needing home health care significantly gives stress to parents of children without autism. Results of the analysis for this thesis demonstrates that parents of children with autism, whose children needed physical, occupational or speech therapy, and respite care, reported more significant odds of parenting stress than those who did not need such auxiliary care services. In the other stratification (children without

autism), needing therapies, respite care, or genetic counseling all give a higher odds of parenting stress compared to those whose children did not need them. Generally, such services serve as first aid management programs and sometimes good substitutes for the needed social support for most parents.

As discussed in the opening paragraphs of this discussion, communication and language problems are major barrier to mitigating parenting stress. Parents of children with autism with Spanish as their primary language reported more odds of stress than those with English as their primary language. Given that English is the primary language for most care providers especially specialist care providers, it is imperative to hire interpreters at provider's offices for parents with Spanish as primary language. However, due to cost implications and lack of personnel most providers may operate without such services. Future questionnaires administered in other languages should read to respondents in the primary language spoken in the households. Finally, from the results of this thesis, satisfaction with child health services was also reported as one of the major indicators of stress. Since empirical evidence suggests that provision of satisfactory health care services to meet individual or family health care needs drives demand, conscious efforts must be made to intensify research into more efficacious intervention procedures that would satisfy the health needs of parents. Specifically, findings from this thesis demonstrated and attested to the fact that both parents of children with and without autism, who were not satisfied with child health care services experience more stress odds than those parents who were relatively satisfied with the existing child health services.

This thesis is subject to several limitations. The first and most important one is the inability to measure and quantify stress. Lack of this stress measuring parameter made it impossible to compare levels of parenting stress, especially among age groups and between sexes. Parameters used to compose stress for the analysis were based on empirical evidence rather than scientifically designed parameter. Data itself was self-reported by phone which sets limit and excludes respondents without home phones or with phones, which are not listed in the optional public phone directory. Secondly, information on the health of respondents may be based on access to appropriate diagnostic health or educational services. Language communication about health status may also limit pertinent and volume of information provided. Given that data used for this thesis is a secondary data, and therefore cross-sectional study, temporality of associations between exposure and outcome could not be verified. Finally, components of respondent data were intentionally deleted or obscured from the public domain for the purposes of protecting human subjects due to Katrina, Ike and Rita hurricane negative experiences. Some supplemental questionnaires had to be redesigned for such subjects.

Conclusions

Consistent with Brach, Fraser, and Paez, (2005) and Pottie (2007), findings of this research indicated language communication as a major barrier in health delivery and also a major factor that explains parenting stress. Specifically, this study suggests that parenting children with autism has such stress indicators as: problems with insurance access, cultural sensitivity of care providers and language communications. Analysis of

this CSHCN 2005-2006 sample also suggested needs for home health care, medical supplies, respite care physical, occupational and speech therapy. Future studies are needed to expand and confirm these findings. Finally, given that there is no authentic literature to support the measurement for the stress variable used in this study, it is worth emphasizing that future health care studies would focus on designing measurements, which can define and quantify stress more accurately. This more scientific parameter, if designed, will be helpful to better understand studies on such all important subject matter.

APPENDIX A

NS-CSHCN (2005-2006)

QUESTIONNAIRES ON VARIABLES USED IN THE MODEL

Questionnaires on Dependent (Stress Defining) Variables

C9Q04: How many hours per week do you or other family members spend Arranging or Coordinating (S.C.)'s Care? (By this I mean making Appointments, making sure that Care Providers are Exchanging Information, and following up on (S.C.)'s Health Care Needs).

Response Options: (000) Less than One Hour, (168) Around the Clock, (555) None / Does Not Arrange Coordinate Care, (996) Don't Know, (997) Refused.

C9Q05: Have (S.C.)'s health conditions caused Financial Problems for your Family?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C9Q06: Have you or Other Family Members Cut Down on the Hours you Work because of (S.C.)'s Health?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C9Q07: Have you Needed Additional Income to cover (S.C.)'s Medical Expenses?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C9Q10: Have you or Other Family Members Stopped Working because of (S.C.)'s Health?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

Questionnaires on Independent Variables

C4Q05_X01: During the past 12 months when (S.C.) was younger than 12 months, since (his/her) birth, was there any time when (S.C.) Needed Routine Preventive Care, such as a physical examination or well child check-up?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C4Q05_X04: During the past 12 months, when (S.C.) is younger than 12 months, since (his/her) birth, was there any time when (S.C.) Needed Prescription Medications?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C4Q05_X05: During the past 12 months when (S.C.) is younger than 12 months since (his /her) birth, was there any time when (S.C.) Needed Physical, Occupational or Speech Therapy?

Response Options: (1) Yes, (0) No, (6) Don't Know.

C4Q05_X08: During the past 12 months when (S.C.) is younger than 12 months, since (his /she) birth, was there any time when (S.C.) Needed Home Health Care?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C4Q05_X13: (During the past 12 months, when (S.C.) is younger than 12 months since (his/her) birth, was there any time when (S.C.) Needed) Medical Supplies?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused. Some examples of Medical Supplies include Bandages and Sponges. These are items that are Disposable. This does not include Prescription Medication.

C4Q06_X01: During the past 12 months when (S.C.) is younger than 12 months since (his/her) birth, was there any time when you or Other Family Members Needed Respite Care? (Respite Care is care for the child so the family can have a break from ongoing care of the child. Respite Care can be thought of as Child Care or Babysitting by someone trained to meet any special needs the child may have. Both Professional and Non-professional Respite Care should be included.

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C4Q06_X02: During the past 12 months, when (S.C.) is younger than 12 months since (his/her) birth, was there any time when you or Other Family Members Needed Genetic Counseling for advice about Inherited Conditions Related to (SC)'s Medical, Behavioral, or Other Health Conditions?

Response Options: (1) Yes, (0) No, (6) Don't Know, (7) Refused.

C6Q0C: Thinking about (S.C.)'s Health Needs and the Services (he/she) receives, how Satisfied or Dissatisfied are you with those Services? Would you say Very Satisfied, Somewhat Satisfied, Somewhat Dissatisfied or Very Dissatisfied?

Response Options: (1) Very Satisfied, (2) Somewhat Satisfied, (3) Somewhat Dissatisfied, (4) Very Dissatisfied, (6) Don't Know, (7) Refused.

UNINS_YR (C7Q12): During the past 12 months when (S.C.) is younger than 12 months since (his/her) birth, about how many months was (S.C.) Without Any Health Insurance or Coverage?

Response Options: (1) 6 Months or Less, (2) More than 6 Months, but Not More than 6 Months or Less, (3) More than 6 Months, but Less than 1 Year, (4) 1 Year or More.

C2Q05R: What is the primary language spoken in your home?

Response Options: (1) English, (2) Spanish, (3) Any Other Language, (6) Don't Know, (7) Refused

AGE (1 – 5 Years): How many children between the ages of 12 months and 5 years old are living or staying in your household?

Response Options: (1) If One or More, Enter # of Children.____ (Enter 1 to 9), (2) If No Children Enter 0, (96) Don't Know, (97) Refused.

AGE (6 – 11 Years): How many children between the ages of 6 years and 11 years old are living or staying in your household?

Response Options: (1) If One or More, Enter # of Children. ____ (Enter 1 to 9), (2) If No Children Enter 0, (96) Don't Know, (97) Refused.

AGE (12 – 17 Years): How many children between the ages of 12 years and 17 years old are living or staying in your household?

Response Options: (1) If One or More, Enter # of Children. ____ (Enter 1 to 9), (2) If No Children Enter 0, (96) Don't Know, (97) Refused.

NRACER (Ethnicity/Race Combined with Hispanic): Now, I'm going to read a list of categories. Please choose one or more of the following categories to describe (S.C.)'s race. Is (S.C.) White, Black or African American, American Indian, Hispanic, (Alaska Native, Asian, Native Hawaiian or other Pacific Islander)?

Response Options: (1) White, (2) Black or African American (3) Hispanic, (4) Others

OTH LANGR (Other Languages other English of Interview):

Response Options: (1) English, (2) Other Languages.

APPENDIX B
LIST OF TABLES

**TABLE 1: DEFINITION AND FREQUENCY OF DEPENDENT VARIABLES WHICH DEFINED STRESS
(RESPONSE AMONG SAMPLED POPULATION OF PARENTS OF CHILDREN WITH AUTISM)**

Variable	Definition of Variable as in the Interview Questionnaires	Freq. (n)	Yes	(%)	No	(%)
C9Q05	Child's Health Care Has Caused Financial Problems	40,723	826	2.07	1275	3.19
C9Q06	Family Members Have Cut Work Hours to Care for Child	40,723	740	1.82	1365	3.42
C9Q07	Needed Additional Income for Child's Medical Expenses	40,723	695	1.74	1407	3.52
C9Q10	Family Member Stopped Working Due to Child's Health	40,723	749	1.87	1357	3.39

Table 1 above shows information on definition, response frequency and percentage of the dependent variables. Affirmative (Yes) responses any one these variables constitute stress (STRESS). STRESS was used in the final model as the single dependent variable.

TABLE 2: FREQUENCY OF DEMOGRAPHIC STRESS INDICATING VARIABLES

Variable	Stress (Yes)		Total (Y/N)	
	n	(%)	n	(%)
AUTISM				
No	12001	31.91	38133	94.60
Yes	1411	68.57	2123	5.40
Total			40256	100
AGE				
0-5 Yrs	2676	36.40	7416	23.64
6-11 Yrs	2693	34.38	7824	21.46
12-17 Yrs	6770	33.32	20959	54.90
Total			36199	100
SEX				
Male	8244	34.42	24150	59.36
Female	5389	33.27	16498	40.64
Total			40648	100
RACE				
White	9223	31.92	29119	65.30
Black/African-American	1516	36.13	4204	16.24
Hispanics	1707	41.75	4016	11.78
Others	1134	36.25	3193	6.68
Total			40532	100
PRIMARY LANGUAGE				
English	12933	33.32	39370	95.30
Spanish	721	51.09	1326	4.70
Total			40696	100
INTERVIEW QUESTIONNAIRES IN OTHER LANGUAGES				
No	13088	33.55	39391	96.33
Yes	545	52.13	997	3.67
Total	13633	34.23	40388	100

TABLE 3: FREQUENCY OF OTHER STRESS INDICATING VARIABLES

Variable	Stress (Yes)		Total (Y/N)	
	n	(%)	n	(%)
EDUCATION				
Less than High School	800	42.38	1908	6.83
High School Grad	2394	37.52	6449	23.09
More than High School	10439	32.26	32284	70.08
Total			40641	100
HEALTH INSURANCE				
Insured Entire Year	11672	31.87	37168	91.19
Not Insured at Some Pt. During the Year	1930	57.56	3395	8.82
Total			40563	100
SATISFACTION WITH CHD HEALTH SERVICES				
Very Satisfied	5919	25.29	24032	59.80
Somewhat Satisfied	5355	43.35	12346	31.46
Somewhat Dissatisfied	1416	66.78	2180	5.54
Very Dissatisfied	749	62.83	1176	3.20
Total			39734	100
PROV. SENSITIVE TO FAM. VAL. & CUSTOMS				
Never	435	53.83	768	2.32
Sometimes	1651	52.38	3041	8.75
Usually	3480	41.50	8488	21.36
Always	7469	29.32	26258	67.58
Total			38555	100

TABLE 4: FREQUENCY OF NEEDS FOR CARE AS STRESS INDICATING VARIABLES

Variable	Stress (Yes)		Total (Y/N)	
	n	(%)	n	(%)
NEED FOR ROUTINE PREVENTIVE CARE				
No	2934	33.36	8958	22.14
Yes	10695	34.40	31660	77.86
Total			40618	100
NEED FOR PRESCRIPTION MEDICATION				
No	1814	34.96	5229	13.63
Yes	11829	34.07	35430	86.37
Total			40659	100
NEED FOR PHYS. OCCUP/ SPEECH THERAPY				
No	8804	28.46	31523	77.17
Yes	4831	53.37	9142	22.83
Total			40665	100
NEED FOR HOME HEALTH CARE				
No	12535	32.66	38982	95.51
Yes	1108	65.97	1690	4.49
Total			40672	100
NEED FOR OTHER MEDICAL SUPPLIES				
No	9924	30.64	32927	81.40
Yes	3724	49.51	7760	18.60
Total			40687	100
NEED FOR RESPITE CARE				
No	12275	32.10	38902	95.46
Yes	1383	77.54	1810	4.54
Total			40712	100
GENETIC PROBLEM REQUIRING COUNSELING				
No	12173	32.28	38452	94.34
Yes	1447	63.33	2214	5.66
Total			40666	100

TABLE 5: RESULTS OF THE UNADJUSTED STRESS VERSUS RESPONSE VARIABLE ASSOCIATIONS

Variables	Unadjusted Odds Ratio Values		
	OR Estimate	P-Value	95% CI
Autism		< 0.0001	
Yes versus No	4.65		(4.00, 5.41)
Age		0.0161	
Age: 0-5 versus 12-17 Years	1.15		(1.04, 1.26)
Age: 6-11 versus 12-17 Years	1.05		(0.96, 1.15)
Sex		0.0743	
Sex: Male versus Female	1.07		(0.99, 1.15)
Race		< 0.0001	
Black or African American versus White	1.21		(1.09, 1.34)
Hispanic versus White	1.53		(1.36, 1.72)
Others versus White	1.21		(1.06, 1.40)
Primary Language		< 0.0001	
Spanish versus English	2.09		(1.73, 2.52)
Interview Questionnaires in Other Languages		< 0.0001	
Yes versus No	2.16		(1.75, 2.66)
Education		< 0.0001	
Education: High School versus > High School	1.26		(1.16, 1.38)
Education: < High School versus > High School	1.55		(1.33, 1.80)
Health Insurance Status		< 0.0001	
Insured Entire Yr. versus Some Pt. in the Yr.	0.35		(0.31, 0.39)
Routine Preventive Care		0.2792	
Yes versus No	1.05		(0.96, 1.14)
Prescription Medication		0.4598	
Yes versus No	0.96		(0.87, 1.07)
Physical Occupational or Speech Therapy		< 0.0001	
Yes versus No	2.88		(2.65, 3.12)
Home Health Care		< 0.0001	
Yes versus No	4.0		(3.35, 4.76)
Medical Supplies		< 0.0001	
Yes versus No	2.22		(2.04, 2.42)

TABLE 6: STRESS VERSUS STRESS INDICATOR ASSOCIATIONS WITH ONE ANOTHER

Association P-Values: Autism with Other Stress Indicating Variables	
Variables	Association P-Value
Age	
Autism with Age	0.2252
Sex	
Autism with Sex	0.6494
Race	
Autism with Race	0.9498
Education	
Autism with Education	0.9214
Health Insurance	
Autism with Health Insurance	0.6449
English/Spanish as Primary Language	
Autism with Primary Language	0.0212
Routine Preventive Care	
Autism with Preventive Care	0.3139
Prescription Medication	
Autism with Prescription Med.	0.0115
Physical Occupational/Speech Therapy	
Autism with Phys. Occupational / Speech Therapy	0.8197
Home Health Care	
Autism with Home Health Care	0.0068
Medical Supplies	
Autism with Medical Supplies	0.7890
Respite Care	
Autism with Respite Care	0.6085
Genetic Counseling	
Autism with Genetic Counseling	0.0123
Satisfaction with Child's Health Care Services	
Autism with Sat with Child's H. Care Services	0.7172
Providers' Sensitivity to Family's Values & Customs	
Autism with Prov. Sensitive To Family Values	0.1356
Quest. In Other Languages	
Autism with Other Languages	0.3163

TABLE 7: ADJUSTED ODDS ASSOCIATIONS: STRESS & STRESS INDICATORS AT 95% CI & P-VALUES

Variables	Autism					
	Yes			No		
	AOR*Est.	P-Value	95% CI	AOR Est.	P-Value	95% CI
Age		0.1542			0.3792	
Age: 0-5 vs. 12-17 Yrs.	1.61		(0.99, 2.63)	1.06		(0.94, 1.18)
Age: 6-11 vs. 12-17 Yrs.	1.10		(0.70, 1.75)	1.08		(0.96, 1.20)
Sex		0.7100			0.6496	
Sex: Male vs. Female	1.09		(0.69, 1.72)	0.98		(0.90, 1.07)
Race		0.9548			0.7283	
Black or African American vs. White	1.00		(0.59, 1.70)	1.08		(0.94, 1.24)
Hispanic vs. White	0.82		(0.41, 1.66)	1.01		(0.84, 1.21)
Others vs. White	1.03		(0.51, 2.09)	1.05		(0.88, 1.26)
Primary Language		0.0027			0.0087	
Spanish vs. English	9.44		(2.18, 40.96)	1.61		(1.13, 2.30)
Int. Questionnaires in Other Lang.		0.2694			0.7555	
Yes vs. No	0.40		(0.08, 2.02)	0.94		(0.62, 1.42)
Education		0.6090			< 0.0001	
Education: H. School vs. > H. School	1.26		(0.80, 1.98)	1.27		(1.13, 1.42)
Education: < H. School vs. > H. School	1.16		(0.54, 2.48)	1.36		(1.10, 1.68)
Health Insurance Status		0.0160			< 0.0001	
Insured Entire Yr. vs. Some Pt. in the Yr.	0.34		(0.14, 0.82)	0.42		(0.36, 0.49)
Sat. with Child's Health Care Svcs.		< 0.0001			< 0.0001	
Somewhat Dissat. vs. Very Dissatisfied	0.96		(0.39, 2.36)	1.02		(0.75, 1.39)
Somewhat Satisfied vs. Very Dissatisfied	0.59		(0.26, 1.37)	0.47		(0.36, 0.60)
Very Satisfied vs. Very Dissatisfied	0.27		(0.11, 0.65)	0.26		(0.20, 0.33)
Providers' Sen. to Fam's Val. / Custs.		0.0295			< 0.0001	
Always vs. Never	1.68		(0.72, 3.90)	0.73		(0.53, 0.99)
Sometimes vs. Never	2.56		(1.01, 6.48)	1.00		(0.71, 1.40)
Usually vs. Never	2.79		(1.17, 6.64)	0.94		(0.69, 1.30)

* Adjusted Odds Associations = Adjusted Odds Ratios

TABLE 8: ADJ. ODDS ASSOC.: STRESS & CARE NEEDS STRESS INDICATORS AT 95% CI & P-VALUES

Variables	Autism					
	Yes			No		
	AOR* Est.	P-Value	95% CI	AOR Est.	P-Value	95% CI
Need Routine Preventive Care		0.2233			0.4713	
Yes vs. No	1.31		(0.85, 2.01)	1.04		(0.93, 1.16)
Need Prescription Medication		0.0006			0.0325	
Yes vs. No	2.07		(1.36, 3.14)	1.17		(1.01, 1.36)
Need Phy. Occup. / Speech Therapy		0.0031			< 0.0001	
Yes vs. No	1.83		(1.23, 2.74)	1.92		(1.73, 2.15)
Need Home Health Care		0.4664			< 0.0001	
Yes vs. No	0.79		(0.42, 1.49)	1.98		(1.57, 2.50)
Need Medical Supplies		0.0367			< 0.0001	
Yes vs. No	1.84		(1.04, 3.27)	1.99		(1.79, 2.22)
Need Respite Care		< 0.0001			< 0.0001	
Yes vs. No	3.71		(2.18, 6.30)	3.17		(2.40, 4.19)
Need Genetic Counseling		0.7797			< 0.0001	
Yes vs. No	0.91		(0.48, 1.73)	2.14		(1.73, 2.66)

* AOR = Adjusted Odds Ratio

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