The relationship between healthcare services and financial burden among families of children with autism spectrum disorders: A US perspective

Darshini Dhanraj Shah

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THE RELATIONSHIP BETWEEN HEALTHCARE SERVICES AND
FINANCIAL BURDEN AMONG FAMILIES OF CHILDREN WITH
AUTISM SPECTRUM DISORDERS: A US PERSPECTIVE

A Thesis
Submitted to the Mylan School of Pharmacy

Duquesne University

In partial fulfillment of the requirements for
the degree of Master of Science

By
Darshini Shah

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THE RELATIONSHIP BETWEEN HEALTHCARE SERVICES AND
FINANCIAL BURDEN AMONG FAMILIES OF CHILDREN WITH
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ABSTRACT

THE RELATIONSHIP BETWEEN HEALTHCARE SERVICES AND FINANCIAL BURDEN AMONG FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS: A US PERSPECTIVE

By
Darshini Shah

December 2016

Thesis supervised by Dr. Vincent Giannetti

OBJECTIVE: The research was designed to determine the financial burden among families of children with ASD and to identify the predictors of financial burden

METHODS: Children with a confirmed diagnosis of ASD were identified in the Interaction Autism Network Registry. Multiple regression analyses was used to determine the association between financial burden and coordination of care, quality of healthcare interactions, adequacy of insurance, and adequacy of medical insurance coverage

RESULTS: Families of children diagnosed as having ASD reported higher financial burden as compared to other developmental disorders. The financial burden was significantly associated with various facets of healthcare provision

CONCLUSIONS: The findings highlight the role of coordinated care, access to care, and quality of healthcare interactions in improving caregiver burden.
DEDICATION

To my family
ACKNOWLEDGEMENT

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LIST OF ABBREVIATIONS

ABA: Applied Behavioral Analysis
AD: Autistic disorder
ADI-R: Autism Diagnostic Interview-Revised
ADOS: Autism Diagnostic Observation Schedule
ASD: Autism Spectrum Disorder
CDC: Center for Disease Control and Prevention
DDs: Developmental disabilities
DSM: Diagnostic Statistical Manual
ID: Identification
IOM: Institute of Medicine
M-CHAT-R: Modified Checklist for Autism in Toddlers, Revised
MHCs: Major health complications
OT: Occupational therapy
PDD-NOS: Pervasive developmental disorder – not otherwise specified
PT: Physical therapy
SCQ: Social communication questionnaire
SRS: Social responsiveness scale
TEACCH: Treatment and Education of Autistic and Communication-related Handicapped Children program
UCLA: University of California Los Angeles
US: United States
CHAPTER ONE – INTRODUCTION

**Background**

Autism Spectrum Disorders (ASD) is a group of neurological disorders caused by the atypical development of the brain in early childhood.\(^1\) ASD is characterized by impairment in communication such as providing inappropriate responses in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age.\(^2\) In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items.\(^2\) This is cause for concern as it may lead to significant difficulties in learning essential skills and living independently. ASD is known to be a spectrum disorder because not all ASD patients manifest the same symptoms; instead patients usually present varying number of symptoms and with a varying level of severity. According to the Diagnostic Statistical Manual (DSM) – V criteria, people with ASD must show these symptoms starting from early childhood, even if they are recognized later in life.\(^2\)

**Burden of illness**

The prevalence estimates vary based on the method of estimation. In 2014, the proportion of children between the ages of 3-17 years diagnosed with ASD in the United States (US) was estimated to be 1 in 45. Additionally, the prevalence of ASD among 8-year olds has been estimated to be 1 in 68.\(^3,4\) ASD occurs more frequently among boys as compared to girls with a an estimated male-to-female prevalence ratio of 3:1 nationwide.\(^4\) Among the overall ASD population, the distribution by race/ethnicity was estimated to be 55.3% in non-Hispanic Caucasians, 20.9% in non-Hispanic African-Americans and 18.9% in
Hispanic children. The prevalence of ASD in the US has recently risen, increasing from 6.7 per 1000 in 2000 to 14.7 per 1000 persons in 2010. The rise in prevalence, in part, may be attributed to the availability of better diagnostic instruments, such as Autism Diagnostic Observation Schedule (ADOS) and Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R). However, even after accounting for the availability of better diagnostic instruments, the rise in ASD prevalence has been higher than expected and has caused concern among policymakers.

Cost of illness

The annual societal cost of ASD in the US is estimated to be $137 billion. Societal costs include all costs borne by all stakeholders such as direct medical costs, direct non-medical costs, and indirect costs. In 2011, the total annual cost of caring for a child with ASD was estimated to be $17,000 higher than the cost of caring for a child without ASD. The lifetime societal cost of autism in the US has been calculated at approximately $3.2 million for one child using 2003 data, with the majority of ASD-related costs attributable to lost productivity of patients during the course of their lifetime.

Direct costs

Direct costs include healthcare costs and all costs not directly related to medical services such as transportation and special educational services. In the year 1999-2000, the total annual healthcare cost in the US children with autism vs. children without ASD was found to be $6,132 vs. $860, respectively. Another study found that the main predictors of costs were school services with nearly 76% children with ASD receiving specialized educational program as compared to 8% children without ASD, thereby, accounting for $8610 in higher costs among children with ASD. Furthermore, the costs were also found
to vary significantly by the level of severity, with the most severe patients reporting highest non-healthcare costs in all categories (Figure 1).
Indirect costs

Indirect costs are opportunity attributable to work productivity due to a health disorder or due to taking care of someone with a health disorder. Based on studies using national samples from 2002-2008, families of children with autism were found to earn 28% less overall as compared to families of children without developmental problems and 21% less than families of children with another health limitation. The difference is more stark in case of mothers of children with autism, with 56% less earnings as compared to mothers of children with no limitations, and 35% less than mothers of children with another health limitation. Another study observed that while there was no significant difference in caregiving time with families of children with and without ASD, families of children with ASD reported greater time on ASD-specific caregiving activities such as
family-based therapies and coordinating medical services and less time on general activities of daily living and caregiving as compared to children without ASD.\(^\text{10}\)

\textit{Causes and Risk Factors}

Despite significant research, the etiology of ASD remains unclear. Current evidence suggests that ASD may be caused by a mix of genetic and environmental factors. Studies have reported that there is a 36-92\% chance of being affected by ASD if an identical twin has an ASD and up to 31\% chance if a non-identical twin has an ASD.\(^\text{12-15}\) Additionally, siblings of children with ASD have a 2-18\% chance of being affected by ASD.\(^\text{16,17}\) This suggests that there may be a genetic basis for the causation of ASD. However, the absence of 100\% concordance of ASD among identical twins suggests that environmental factors in addition to genetic mutations may be involved in the causation of autism. Environmental factors can be classified into three types of exposures: prenatal, perinatal, and neonatal.\(^\text{18}\)

Prenatal exposures are chemicals or microbes that a child may be exposed to during the gestation period. An increased incidence of ASD was identified in children with prenatal exposure to thalidomide, hospitalization due to infection, rubella infection, misoprostol, chlorpyrifos, and valproic acid.\(^\text{19-28}\) In addition to medication exposures, increased incidence of ASD was found in the children whose mothers had metabolic disorders such as diabetes, hypertension and obesity during pregnancy. In particular, obese women were 1.6 times more likely to give birth to a child with an ASD or a neurodevelopmental disorder than women who were not obese.\(^\text{29,30}\) In addition, inefficient folate metabolism coupled with low folic acid intake during pregnancy was associated with an increased risk of ASD.\(^\text{31}\) Other prenatal factors that have been found to be linked with ASD are advanced parental age at birth and parity.\(^\text{30,32-35}\) Perinatal factors comprise of events or
exposures that occur during birth. Perinatal factors that inflict a higher risk of ASD are prolonged labor, breech presentation, injury or trauma during birth, maternal hemorrhage and gestational age with preterm babies being more likely to have ASD.\textsuperscript{34,36–38} In addition, children with low birth weight were twice as likely to have ASD as compared to children with normal birth weight. Neonatal factors are disease conditions or exposures after birth such as having a heart dysfunction, infection, respiratory distress, and anemia. Seizures occurring early in life were associated with an increased risk of ASD.\textsuperscript{30,37} Despite concerns about the possibility of links between vaccines and ASD, studies conducted by the Center for Disease Control and Prevention (CDC) and Institute of Medicine (IOM) have shown that vaccines do not cause ASD.\textsuperscript{39}

\textit{Diagnosis}

There is no reliable biological test for the diagnosis of ASD as no biomarker(s) have been identified that specifically indicate the presence of autism. As a result, the diagnosis is dependent on observation alone. As per DSM-V criteria, an autism diagnosis can be made if a child is known to exhibit persistent deficit in social communication and repetitive behaviors, starting in early childhood, which cannot be accounted for by intellectual disability or global developmental disorder. The severity of ASD is further classified on the basis of the level of support required:

- Severity level 1: Requiring some support
- Severity level 2: Requiring substantial support
- Severity level 3: Requiring very substantial support

It is worth noting that the DSM-V classification of ASD differs from the earlier classification, the DSM-IV TR criteria. The DSM-V classification no longer divides ASD
into three different disease entities: Autistic disorder (AD), Asperger’s syndrome and Pervasive developmental disorder – Not Otherwise Specified (PDD-NOS). Instead, under the new classification system, all ASDs are classified as one disease entity with differing levels of severity.\(^{40}\)

Early diagnosis of ASD is critical for a number of reasons. The most important reason is that early interventions have shown to improve the functioning in children with ASD.\(^{41}\) In addition, there is evidence that early interventions have better long-term prognosis and are cost-effective.\(^{42}\) In 2001, the average age at diagnosis was 5 years.\(^{41}\) With increasing awareness of ASD and the development of new reliable and valid instruments such as Autism Diagnostic Observation Schedule (ADOS) for diagnosis, a large number of children are being diagnosed earlier. The average age for diagnosis of autism was 3.1 years in 2004.\(^{41}\) Studies have shown that a reliable and valid diagnosis for autism in a child can be obtained at 2 years. The diagnosis obtained at 2 years was found to be stable at the age of 9 years.\(^{41}\) The two commonly used instruments for diagnosis are: Autism Diagnostic Interview-Revised (ADI-R) and Autism Diagnostic Observation Schedule (ADOS).\(^{43,44,45}\) ADI-R is a semi-structured interview which is administered to parents by the clinician. The instrument is appropriate for administration in reference to any child whose mental age is at least 18 months.\(^{44}\) ADOS is used in a clinical environment to establish a diagnosis based on observation and interaction with the child. The instrument relies on the use of age appropriate play activities to establish a diagnosis. ADOS has been widely regarded as a gold standard for the diagnosis of ASD; however, it has limited applicability in toddlers.\(^{45}\) Newer diagnostic tools such as M-CHAT and ADOS-2 have
been designed with a goal of obtaining a reliable diagnosis of autism in toddlers as young as 16-30 months old.\textsuperscript{46,47}

**Disease Management**

The symptoms of ASD include impairments in three core domains, including social skills, language, and behavior. In addition, there may also be deficits in cognitive ability and sensory perceptions among children. ASD represents a spectrum of disorders, which means that patients may exhibit a different number of core and allied symptoms and the levels of severity of deficits may differ as well. Accordingly, interventions may be targeted at alleviating deficits in core symptoms or one of the allied symptoms or a combination of treatments may be utilized.\textsuperscript{48,49} Treatment goals are based on the symptoms manifested. Interventions are usually designed to achieve one of the following:

1. **Improving functional abilities in one or more of the following domains:**
   - academic skills, communication skills, higher cognitive function, interpersonal skills, learning readiness, motor skills, personal responsibility, play, placement in schools, self-regulation.\textsuperscript{48}

2. **Reducing undesirable behaviors:** such as problem behaviors, restricted, repetitive, nonfunctional patterns of behavior, interests, or activity (RRN).\textsuperscript{48}

Generally, interventions may focus on one or more of the areas mentioned above. Interventions for ASD are divided into five categories: behavioral, educational, medical and related, allied health, and complementary and alternative medicine.

1. **Behavioral interventions:** Over the course of their development, children tend to experiment with behaviors. The behaviors may be acceptable or unacceptable.\textsuperscript{50}

   Usually, the acceptable behaviors are encouraged by subtle positive
reinforcements and the unacceptable behaviors are discouraged by punishments of negative reinforcements.\textsuperscript{50} Children with ASD have difficulty interpreting the environmental stimuli and hence, intensive behavioral interventions are needed.\textsuperscript{50} Behavioral interventions are based on the principles of applied behavioral analysis (ABA).\textsuperscript{51} ABA is focused on teaching children to maintain performance of acceptable behaviors and reduce unacceptable behaviors. ABA uses reinforcement, shaping, prompting and prompt-fading, and generalization as teaching techniques.\textsuperscript{51} In addition, ABA helps children maintain the behaviors taught in different settings. There is preliminary evidence that early intensive behavior and developmental interventions improve core deficits among children with ASD.\textsuperscript{44–54} Interventions that fall in this category are: University of California Los Angeles (UCLA)/Lovaas model, Early Start Denver Model, Pivotal Response Treatment, Joint Attention Intervention, and Cognitive Behavioral Treatment.\textsuperscript{49}

2. \textbf{Educational interventions:} Educational interventions are administered primarily in an educational setting with the intent of improving academic and cognitive skills. The main focus is improving personal independence and social responsibility.\textsuperscript{49,63} Some programs have focused on addressing social and behavioral issues arising in the classroom setting.\textsuperscript{64} The most widely applied educational intervention is the Treatment and Education of Autistic and Communication-related Handicapped Children (TEACCH) program.\textsuperscript{64} TEACCH involves structured teaching which is based on the fact that children on the spectrum have difficulty in perception and understanding. As a result, the teaching methods incorporate picture schedules and physical supports that provide a unique learning opportunity for children.\textsuperscript{64} In
general, educational interventions are classroom-based or computer-based approaches usually based on the principles of ABA such as providing reinforcements to help children learn.49

3. **Medical and related intervention:** Medical and related interventions is a category of interventions that comprises any intervention involving the administration of an external substance to treat the symptoms of ASD.48,49 Medical and related intervention include medications, supplements, specialized diets or other treatments such as hyperbaric oxygen.48,49 The medications that are most commonly used to treat symptoms of ASD are antipsychotics, serotonin reuptake inhibitors (SRI) and psychostimulants.48,49 Other medical interventions such as immunoglobulin, hormonal treatments and gluten free casein free diets have also been used to treat ASD.48,49 Medical and related interventions are generally recommended for children with severe behavioral problem.48,49 Antipsychotics, SRI and psychostimulants act by controlling hyperactivity and challenging behaviors.48,49 Medications are often used in conjunction with other behavioral and allied health interventions.48,49

4. **Allied health interventions:** Allied health interventions are aimed at overcoming core deficits of ASD.48,49 These interventions are roughly divided into three categories: interventions to improve language, sensory or auditory integration techniques, and other approaches that address multiple limitations.48,49 These are administered by allied health professionals such as speech therapist, physical therapist, and occupational therapist.48,49 Few examples of allied health
interventions are: sensory integrations, auditory integrations, speech therapy, music therapy, and picture exchange communication systems.\textsuperscript{48,49}

5. **Complementary Alternative Medicine (CAM):** CAM interventions comprises an array of healthcare approaches outside mainstream western medicine that may be used along with or in place of conventional medicine.\textsuperscript{48,49} Use of CAM therapies is common in children with ASD.\textsuperscript{48,49} The therapies that have been known to be used in ASD are aromatherapy, dance therapy, massage therapy, acupuncture. The modality of action of these interventions is not known.\textsuperscript{48,49}

**Problem statement**

Due to the spectrum of disabilities in children with ASD, the treatment protocol for each child is individualized and diverse. Often times, children are simultaneously prescribed a number of treatments to tackle different issues. Due to treatment complexity, parents have to spend a significant amount to time arranging and coordinating treatment. In addition, parents act as informal caregivers and provide specialized care at home. As such, parents take on multiple roles within caregiving. Meeting the high care demands of children with ASD requires much time, effort and patience. This often results in psychological distress, depression, anxiety and other mental or physical health problems in parents.\textsuperscript{65,66} Moreover, due to the high out-of-pocket healthcare expenses, inadequacy of insurance, underemployment or employment loss, families of children with ASD face financial problems.\textsuperscript{6,67} High financial burden can have a significant negative impact on several aspects of the caregiver’s as well as child’s life, including early institutionalization. It is important to understand the predictors of financial burden in order to find strategies to lower caregiver burden among informal caregivers. Quality of
healthcare interactions and coordination of care are two important aspects of healthcare in children with ASD. Identifying predictors can help improve disease management in these patients.

Hypothesis

The overall hypothesis of the study is that certain aspects of the healthcare system, such as coordination of care, access to care, and quality of healthcare interactions are likely to contribute significantly to the financial burden. Coordination of care and quality of healthcare interactions are, in turn, likely to be affected by adequacy of insurance, severity of disease, and number of co-morbidities.

Research questions

1. To determine the economic impact of ASD on the families of children with ASD
2. To determine the relationship between financial burden among families of children with ASD and coordination of care, unmet needs, access to care, quality of health interactions, and adequacy of insurance
3. To determine the relationship between quality of healthcare interactions and access to care, adequacy of insurance, unmet needs, coordination of care, and severity of disease
4. To determine the relationship between coordination of care and ease of obtaining a referral, access to care, adequacy of insurance, unmet needs, quality of healthcare interactions, and severity of disease
CHAPTER TWO – LITERATURE REVIEW

A detailed literature review was conducted to identify and understand the existing literature related to caregiver burden, quality of care, and the cost of ASD.

Search strategy and inclusion / exclusion criteria

Relevant publications were identified through a search of the literature with PUBMED using the following search terms: (1) Autism* or ASD* or autistic* in combination with (1) cost or economic* (2) caregiver burden* or caregiving* (3) quality of care* or quality of healthcare*. Human studies in English language conducted in the US and published in peer-reviewed journals were included in the initial search. The search was restricted to January 2006 – January 2016. The search yielded 506 hits, to which the following exclusion criteria were applied: (1) non-original research such as letters, commentaries or reviews, (2) not focused on ASD, or (3) not focused on caregiver burden, quality of care or epidemiology. The details of the literature review are described in Figure 2.
Autism + (Caregiver burden OR Quality of care OR epidemiology OR economic): 506 hits

161 titles selected for further abstract review

345 excluded on the basis of title review

101 abstracts selected for full-article review

60 excluded on the basis of abstract review

35 articles included in the full study

- 41 studies conducted outside the US
- 4 not original researches (letters, commentaries, review, etc.)
- 2 not in children
- 5 articles not relevant to the topics focused on in the thesis
- 14 not relevant to the topic

Figure 2: PRISMA diagram for literature review
**Caregiver burden**

Meeting the high care demands of children with ASD requires time, effort, and patience. In addition, parents of children are faced with serious concerns about the child’s future, bullying, and the child’s learning abilities. This often results in psychological distress, depression, anxiety and other mental or physical health problems among parents. Moreover, due to the high out-of-pocket healthcare expenses and underemployment or employment loss, families of children with ASD face financial problems. It is important to measure the caregiver burden in these settings, as caregiver burden and parenting stress can have an impact on the caregivers’ ability to care for the child, especially their ability to provide behavioral treatments. Studies measuring the quality of life among caregivers showed that caregivers of children with ASD showed that a significant proportion of patients with ASD had mental (58%), physical (52%) and financial problems (56%). A majority of caregivers (61%) had difficulty combining activities of daily living and ASD-specific tasks. The measurement of health-related quality of life (HRQoL) and health utilities showed that caregiver of children with ASD had significantly lower HRQoL and utilities as compared to the US population. The main predictors of caregiver burden may be classified into three categories: child-related factors, parental factors, and environmental factors. Child-related factors that have been found to be predictors of caregiver burden are deficits/delays in children’s social relatedness, child’s sensory-related problems and presence of comorbidities. Parental correlates associated with caregiver burden include parenting efficacy, social support, parental attributions, coping styles, and resilience. Environmental factors include respite care and time since child’s ASD diagnosis.
Economic burden associated with ASD

Nineteen studies relevant to the economic burden were identified by the literature review. The studies provided information on financial burden faced by families as well as the economic burden on the healthcare system.

Financial burden on families

The average lifetime cost of ASD has been estimated to be $3.2 million, with the majority of costs being attributed to lost productivity among adults with ASD and parents of children with ASD.\(^7\) Another study found that the discounted lifetime costs for patients with an ASD diagnosis without intellectual disability were $1.43 million in the US.\(^{75}\) The estimated loss of income has been estimated to be between 14% and 28%.\(^6,67\) On average, mothers of children with ASD earn 35% ($7,189) less than the mothers of children with another health limitation and 56% ($14,755) less than the mothers of children with no health limitation.\(^6\) The annual societal cost of childhood ASD was also found to be higher by $17,000 than that in children without ASD and was higher as compared to cost of depression, spina bifida, and mental retardation.\(^{10,8,76}\) Insurance coverage and type of insurance are both important predictors of financial burden among families. A higher per capita Medicaid spending in the state was associated with a lower family burden.\(^{77}\) The out-of-pocket costs were significantly lower among individuals insured by Medicaid as compared to privately insured individuals.\(^{78}\) Families of children living in states with mandates requiring the coverage for ASD were 29% less likely to have out-of-pocket cost greater than $500.\(^{79}\)
Healthcare utilization and economic burden on the healthcare system

Studies have shown that the healthcare utilization and the cost of healthcare of ASD in children was found to be higher as compared to healthcare utilization in children without ASD. The total annual healthcare cost in the US for children with ASD vs. children without ASD was found to be $6,132 vs. $860 in the year 1999-2000 and has increased over the years, showing a 20.4% increase from 2000-2004. Similar results were observed in a population of Medicaid patients with the annual cost of healthcare increasing from $22,079 in 2000 to $22,772 in 2003. The annual total charges of hospitalization in children with ASD was estimated to be $24,862 in 2007. Predictors of costs were identified in several studies. The main predictors of cost in children with ASD were found to be age, insurance coverage, and the presence of co-morbidities. Another potential predictor is the state of residence, whose impact was not well-established with two studies implying no impact on financial burden and two studies demonstrating a significant variation in financial burden based on the state of residence. There was significant difference between healthcare cost to private payers and Medicaid, with cost being almost four times higher among children insured by Medicaid as compared to privately insured individuals ($22,653 vs. $5,254, p<0.0001). The biggest component of the cost difference across Medicaid and private insurance was in outpatient services ($19,948 vs. $3,045, p<0.0001). Psychiatric care costs were over five times higher in Medicaid than in private insurance ($12,851 vs. $2,293, p<0.0001) and were responsible for a larger fraction of total healthcare costs (57% vs. 44% per child with ASD, respectively). Most of this difference in psychiatric care costs was due to differences in outpatient costs. ASD-specific service costs were eight times higher in Medicaid than in
the private sector ($7,438 vs. $928, p<0.0001). Medicaid patients also received significantly more visits for OT/PT, speech therapy and behavior modification treatment than patients enrolled in private insurance. Based on a study conducted in Pennsylvania, it is likely that the passage of a mandate requiring private insurance to cover ASD-related services may reduce state Medicaid expenditures. Another predictor of the medical expenditures associated with ASD was found to be the presence of comorbidities. The type of comorbidities had a significant impact on medical expenditures, with intellectual disability being associated with the highest cost in children with ASD (Figure 3). Discounted lifetime costs for someone with an ASD diagnosis and intellectual disability were $2.44 million in the US. Moreover, the predictors of healthcare costs changed over the course of a lifetime. The utilization of outpatient services significantly declined with each year of age for occupational/physical therapy (9%), speech therapy (8%), mental health services (2%), diagnostic/assessment services (2%), and family therapy (3%). Utilization significantly increased with age for case management/service coordination (2%), medication management (6%), personal care/home health aide (1%), day treatment/partial hospitalization (4%), and respite services (3%). The most dramatic changes in service utilization occurred between the 3–6 year-old and 7–11 year-old age cohorts.
Figure 3: Medical expenditures associated with co-morbidities

Adapted from Peacock et. al. 2012

Quality of care in ASD

Six studies relevant to the quality of care were identified; of these, four studies focused on quality of care in patients with ASD and two studies on the overall quality of care among all children and the predictors. Parental perception of medical encounters is increasingly recognized as an important measure of quality care. Higher patient/caregiver satisfaction with physician interaction can enhance their involvement in self-management. A study conducted among Latino children in the US found that healthcare utilization was mediated by provider interactions. Studies have reported that the quality of healthcare is lower in children with ASD. A single US center in 2002-2003 found that parents of children with ASD reported lower satisfaction with their primary care physicians as compared to parents of children with other developmental disabilities as
well as parents of children with mental retardation. Compared to parents of children with developmental disabilities or mental retardation, parents of children with ASD rated their physicians as worse in terms of physician’s ability to answer questions about the child’s condition, ability to understand how the child’s condition affects the family, and their knowledge of complementary and alternative medicine. A study based on a nationally representative data collected in 2003 demonstrated that patients with ASD were less likely to have a medical home as compared to patients without ASD. In another study based on a nationally representative sample of children with special healthcare needs in the US conducted in 2009-10, quality of care was measured based on three parameters – shared decision-making, coordination of care, and availability of routine care, was lower in children with ASD, with a greater proportion of caregivers of children with ASDs reporting lack of shared decision making (43.1%), as compared to caregivers of children with developmental disabilities (36.4%) and mental health conditions (31.1%). A significantly greater proportion of caregivers of children with ASDs reported lack of coordination (86.7%) as compared to all other groups (82.2% DDs, 61.0% MHCs, and 80.2% both DDs/MHCs). The caregivers of these patients were likely to experience a higher adverse impact. Based on a quality of care study, children with ASD were least likely to have positive scores on the minimal quality index, with only 22% scoring positively. The minimal quality index includes adequacy of insurance, insurance consistency, preventive medical care visits, preventive dental care visits, development screening for young children, access to mental health specialists, and medical home. The age of diagnosis has been considered to be another proxy for quality of care. The age at diagnosis among Medicaid-enrolled children in the US from 2002-2004 was observed
to be around 5.4 years.\textsuperscript{96} Over the three years of the study, the age at diagnosis decreased by 5 months, indicating an improvement in quality of care over time but still more delayed than it should have been.\textsuperscript{96}
CHAPTER THREE – METHODS

The study was a cross-sectional retrospective database study conducted using data from the Interactive Autism Network (IAN).

Data source

Data for the study were obtained from elective online surveys created and hosted by the IAN. IAN is an innovative project bringing together patients and caregivers affected by ASD and researchers involved in ASD research. The IAN research database consists of 54,000 registered members. The members of IAN submit baseline data at joining, such as age of subject, first ASD diagnosis, gender, ethnicity, birth year, race, and state of residence. Following registration, IAN periodically fields questionnaires to members, who may elect participation. Several datasets are maintained by the IAN consisting of questions related to children with ASD, or parents and siblings of children with ASD. The current study is based on general data collected at baseline, detailed diagnosis data, and a survey focused on healthcare access-related issues. The questionnaires used to collect data were either standardized questionnaires, or questionnaires developed in consultation with subject experts. The data used in the study is cross-sectional and has been collected from 2009-2010. Detailed information about the datasets used in this study is described below:

- **Subjects**: The dataset consists of demographic information about the subject who has been diagnosed with ASD. The variables included in this dataset that were used in the analysis are
  - Age of subject (child)
  - Gender
- **Ethnicity**
- **Race**
- **State of residence**

**Child with ASD**: This dataset is focused on the medical history of the child who has been diagnosed with ASD. The questionnaire used to collect the data was administered to parents of the child with ASD. The questionnaire consisted of 65 questions and took approximately 15 mins to complete. The questions are primarily related to the child’s medical history and ASD diagnosis, such as age at first ASD diagnosis, ASD diagnosis, healthcare professional who diagnosed ASD, diagnosis of comorbidities, history of ASD among siblings and cousins. The variables from this questionnaire that were used in the analysis are
  - Year of first ASD diagnosis
  - Number and type of comorbidities

**Social Communication Questionnaire (SCQ)**: This dataset is a standardized questionnaire screening instrument that is used to help identify which children may have ASD. The questionnaire consists of 40 yes/no questions designed to understand the child’s body movements, use of language or gestures, and style of interacting. A SCQ score is known to be correlated with a diagnosis of ASD, with a higher score indicating a higher likelihood of an ASD diagnosis. There are two versions of SCQ – lifetime and current. The lifetime SCQ scores were used in the analysis to provide information about the entire developmental history of the child. The questionnaire is administered to the parents of the child at the time of registration and can be completed in about 10 mins. The SCQ consists of three
domains – behavior, communication, and social interactions. The cut-off score for SCQ has been determined to be 15, with a sensitivity of 0.71 and a specificity of 0.75. SCQ has demonstrated good discriminative validity between ASD and other disorders including non-autistic mild or moderate mental retardation. The total SCQ score and the total score on each of the domains was used for the analysis.

- **Social Responsiveness Scale** The Social Responsiveness Scale (SRS), an important instrument for measuring the social aspects of ASD, is a 65-item rating scale assessing characteristic autistic behavior. Each item is scored from 0 ('never true') to 3 ('almost always true') describing the child’s behavior in the past 6 months. Total scores can range from 0 to 195. The cut-off point that best discriminates children with and without ASD (≥75) was chosen SRS scores discriminate between children with and without ASD and are strongly correlated with the autism diagnostic interview – revised (ADI-R) domain scores (r = 0.65 to 0.77). The SRS is easy to administer and is administered to parents of children aged 4-18 years. The administration time is approximately 15 mins. The variables that were used in the analysis are SRS total score, SRS t-score, and the total and normalized scores on each of the domains.

- **Access to care** This dataset is focused on understanding the barriers to treatment in children with ASD. The dataset contains information about the following concepts:
  - Care coordination
  - Family-centered care
  - Transition issues
Impact on the family

Data access and ethics

The de-identified data was accessed by submitting a data service use agreement and the study was provided an exempt status from the Duquesne University Institutional Review Board (IRB).

Data extraction

The data extraction and analysis was conducted using the software SAS 9.4® (SAS Institute; Cary, NC). The study population consisted of children (age < 18 years) who had a confirmed diagnosis of ASD by a healthcare professional. The five datasets were merged using the variable ‘IAN research ID’. Only children who had complete responses on all five questionnaires were included in the analysis. Records with ≥15% missing data were excluded from the analysis.

Description of variables

Variables relevant to the analysis are described in the following section.

Age of child

Respondents were asked to specify the age of the child with ASD at listing, which was recorded as age_at_listing. The variable age_in_years was calculated based on the age at listing and the time since listing. Age_in_years was defined as a continuous variable.

Age at diagnosis

Respondents were asked to specify the age at which the child was first diagnosed. This variable was recorded as age_first_diagnosis. Age_first_diagnosis was defined as a continuous variable.

Gender of child
Respondents were asked to specify the gender of the child with ASD at listing. The variable was recorded as *gender*. *Gender* was defined as a categorical variable with two levels, 0 and 1, with 0 corresponding to male and 1 corresponding to female.

**Race of child**
Respondents were allowed to select multiple races. Race of the child was recorded by means of several categorical variables. Each variable had two levels, 0 and 1, with 1 corresponding to belonging to a particular race. The races recorded are American Indians and Alaska Natives (*race_ai_an*), Asian (*race_asian*), African American (*race_black_aa*), Native Hawaiian and other Pacific Islanders (*race_nh_pi*), Caucasians (*race_white*), Other (*race_other*), and Unknown (*race_unknown*).

**Ethnicity of child**
Respondents were asked to specify the ethnicity of the child with ASD at listing. The variable was recorded as *ethnicity*. *Ethnicity* was defined as a nominal variable with two levels, Hispanic or Latino and Non-Hispanic

**Total household income**
The total household income was defined as the total combined income including wages, salaries, unemployment payments, public assistance, social security or retirement benefits, and help from relatives. The variable was recorded as a categorical variable, *total_household_income*. *Total_household_income* was defined as a categorical variable with 6 levels: 1 $< 10,000; 2 = 10,000-39,999; 3 = 40,000-69,999; 4 = 70,000-99,999; 5 ≤ $100,000

**Comorbidities**
Respondents has the option of selecting multiple comorbidities. The variable comorbidities were recorded as *comorbidities* and refer to the number of comorbidities.
Comorbidities were calculated based on the sum of several categorical variables: motor delay, cerebral palsy, ADHD, depression, mental retardation, seizures, schizophrenia, tuberous sclerosis, anxiety disorder, and bipolar disorder. Each variable had two levels, 0 and 1, with 1 corresponding to being diagnosed with the particular comorbidity.

**Family reduced working hours**
Respondents were asked if any family members reduced hours of working because of their child’s health. The variable was recorded as a categorical variable, `cut_hours_childs_needs`, with two levels (0 and 1) and 1 corresponding to someone in the family having to cut hours to care for the child with ASD.

**Family stopped working**
Respondents were asked if any family members stopped working because of your child’s health. The variable was recorded as a categorical variable, `fam_stopped_working`. `Fam_stopped_working` has two levels, 0 and 1, with 1 corresponding to someone in the family having to stop working to care for the child with ASD.

**Need more income**
Respondents were asked if they needed additional income to cover your child's care. The variable was recorded as a categorical variable, `need_more_income`, with two levels, 0 and 1, with 1 corresponding to needing more income to care for the child with ASD.

**Financial burden**
Respondents were asked if child's care caused financial problems for the family. The variable was recorded as a categorical variable, `child_health_fin_prob`. `Child_health_fin_prob` had two levels, 0 and 1, with 1 corresponding to having financial problems because of child’s health.

**Out-of-pocket payments**
Respondents were asked about the amount of money paid during the past 12 months for the child's care, including out-of-pocket payments for all types of health-related needs such as co-payments, dental or vision care, medications, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy if any family members stopped working because of your child’s health. This variable did not include health insurance premiums or costs that were or would be reimbursed by insurance or another source. The variable was recorded as a categorical variable, family_paid_all_care. Family_paid_all_care had six levels: 1 = Nothing; 2 < $250; 3 = $250-499; 4 = $500-999; 5 = $1000-4999; 6 ≥ $5000.

**Unmet needs**

Unmet needs was not formally defined in the dataset, but was created as a proxy for access to care for the purpose of data analysis. The variable was recorded as unmetneeds and defined a sum of unmet healthcare needs of the child with ASD or of the families. Respondents were asked about the healthcare services their child needed such as occupational therapy, physical therapy, prescription medicine, etc. This indicated a healthcare need. If the respondents answered yes, they were asked a follow-up questions to determine which of the healthcare needs were met. For each patient, a summation was performed to determine how many healthcare needs were not met. The definition of unmet need is illustrated using the example of mental health services and is described below (Figure 4).
Quality of health interactions

Quality of health interactions was not defined in the dataset, but was created as a proxy for quality of care for the purpose of data analysis. The variable was recorded as *qualityofcare* and defined a sum of the following categorical variables: *doctor_time_child, often_dr_listen, often_dr_sensitive, often_dr_inform, often_dr_partner*. These variables measured how often (never, sometimes, usually, always) doctors or other healthcare providers spent enough time with the child, listened carefully to the parent/caregiver, were sensitive to family values and customs, provided specific information the parent/caregiver requested, and helped the parent/caregiver feel like a partner in the child’s care.

Type of health insurance
Respondents were allowed to select multiple health insurances. Type of health insurance of the child was recorded by means of several categorical variables: type_health_insurance_1, type_health_insurance_2, type_health_insurance_3, type_health_insurance_4, type_health_insurance_5. Each variable had two levels, 0 and 1, with 1 corresponding to having a particular insurance. Insurance provided through an employer or union was recorded as type_health_insurance_1; Medicaid was recorded as type_health_insurance_2; Children’s Health Insurance Program (formerly known as SCHIP) was recorded as type_health_insurance_3; Military Health Plan was recorded as type_health_insurance_4; any other insurance was recorded as type_health_insurance_5.

**Adequacy of insurance**
Respondents were asked if the child’s health insurance offered benefits or covered services that met his/her needs. The variable was recorded as a categorical variable, insurance_meet_needs. Insurance_meet_needs had 4 levels – 1: Never; 2: Sometimes; 3: Usually; 4: Always.

**Delayed or no care**
Respondents were asked if they had delayed or gone without needed care for the child. The variable was recorded as a categorical variable, care_delay_without. Care_delay_without had 2 levels – 0: No; 1: Yes. The variable care_delay_without was used as a proxy for access to healthcare.

**Coordination of care**
Respondents were asked if during the past 12 months, they had felt they could have used extra help with arranging or coordinating child’s healthcare. The variables were categorical and had two levels, 0: No and 1: Yes. If they answered yes, a follow-up question was asked to assess how often they received sufficient help with coordination.
The variable had four levels – 1: Never, 2: Sometimes, 3: Usually, 4: Always. A new variable was created to account for the availability of sufficient coordination. The new variable was recorded as sufficient_coordination. Sufficient_coordination had two levels, 0: insufficient and 1: sufficient coordination. If the response to the first question was 1, and the follow-up question was 3 or 4, parents were considered to have sufficient help with coordination. In some situations, sufficient_coordination was reverse coded to create the variable insufficient_coordination.

Social communication questionnaire
The total score on the social communication questionnaire was recorded as scq_total. scq_total was a continuous variable. The dataset also contained scores on three domains of SCQ – social domain (social_domain), communication domain (communication_domain), and behavior domain (behavior_domain).

Social responsiveness scale
The standardized score on the SRS was recorded as srs_t_score. srs_t_score was a continuous variable. The dataset also contained standardized scores on three domains of SRS – awareness (awareness_t_score), social cognition (social_cognition_t_score), social communication (social_communication_t_score), social motivation (social_motivation_t_score), and autistic mannerisms (autistic_mannerisms_t_score).

Ease of obtaining a referral
A new variable was created to account for ease of referral. The new variable was recorded as ease_ref. Respondents were asked if during the past 12 months, the child needed a referral to see any doctors or receive any services. The variable was categorical and had two levels, 0: No and 1: Yes. If they answered yes, a follow-up question was
asked to assess how much of a problem it was to get referrals. The variable had three levels – 1: Big problem, 2: Small problem, 3: Not a problem.

Data analysis
A descriptive analysis was conducted to identify the demographic characteristics of the children and caregivers including age, gender, race, ethnicity, total household income, comorbidities, quality of health interactions, and unmet needs.

Research objective 1
To determine the economic impact of ASD on the families of children with ASD
Descriptive analyses were conducted to determine the economic impact of ASD in terms of employment outcomes, out-of-pocket payments, financial problems, and need for more income. In addition, an analysis was conducted to measure the relationship between adequacy of insurance and type of health insurance, and the relationship between adequacy of insurance and out-of-pocket costs. A chi-square analysis was used to measure the relationship among the categorical variables.

Research objective 2
To determine the relationship between financial burden among families of children with ASD and coordination of care, unmet needs, access to care, quality of health interactions, adequacy of insurance
A logistic regression analysis was used to determine the predictors of financial burden, a dichotomous variable, among families of children with ASD. The event selected was 1 to model the probability of having financial problems due to the child’s health. The independent variables in the analysis were adequacy of insurance, unmet needs, delaying
care or going without care, quality of healthcare interactions and insufficient help with coordination of care. Dummy variables were used for variables with more than two levels. The assumptions of linear relationship, normality of residuals, and homoscedasticity are not applicable to logistic regression and hence were not included in the analysis. Multicollinearity was assessed using the convergence criterion to ensure that variables were related but not perfectly linear combinations of one another. The primary concern surrounding multicollinearity is that as the degree of multicollinearity increases, the regression model estimates of the coefficients become unstable and the standard errors for the coefficients can be inflated.

**Research objective 3**

*To determine the relationship between quality of healthcare interactions and access to care, adequacy of insurance, unmet needs, coordination of care, severity of disease*

Multiple regression analysis was conducted to determine the predictors of quality of health interactions. Since the quality of health interactions was defined as a sum of five variables (*doctor_time_child, often_dr_listen, often_dr_sensitive, often_dr_inform, often_dr_partner*), an analysis was conducted to evaluate the internal consistency of the measure and the multi-collinearity among the variables used to define quality of healthcare interactions. The methods are described in three steps:

- **Internal consistency of quality of healthcare interactions scale:** The internal consistency of the scale used to define quality of health interactions was tested by calculating the Cronbach’s alpha. Cronbach’s alpha is the average inter-correlation between the individual items of the scale, and it is a measure of how
closely related a set of items are as a group. Cronbach’s alpha > 0.7 is considered acceptable.

- **Multicollinearity diagnostics for quality of health interactions scale:** The multicollinearity of the independent variable was tested using tolerance statistic. The multicollinearity statistics were tested using quality of health interactions scale as the dependent variable and the five variables as independent. The five variables were categorical, hence, each variable was converted to a dummy variable for addition to the regression model.

- **Regression analysis to determine predictors of quality of health interactions scale:** The method used for the regression analysis was orthogonal, which reduces the error sum of squares by adding a variable after all other variables have been added to the model. The dependent variable was quality of healthcare interactions. The independent variables for the regression analysis were as follows: adequacy of insurance, unmet needs, delaying or going without healthcare, sufficient help with coordination, total score on the SCQ scale, score on the social domain on the SCQ scale, score on the communication domain on the SCQ scale, score on the behavior domain on the SCQ scale, total SRS t-score, t-score on the awareness domain, t-score on the social cognition domain, t-score on the social communication domain, t-score on the social motivation domain, and t-score on the autistic mannerisms domain. Dummy variables were used for variables with more than two levels. In order to carry out a linear regression, data should meet the assumption of absence of outliers, linearity, normal distribution of errors, homoscedasticity and multicollinearity. All independent variables of
importance were tested for correlation against the dependent variable. As the presence of outliers in the data is likely to skew the results of regression, all variables were checked for outliers and treated if necessary to eliminate observations containing outlier or capping the values between 1\textsuperscript{st}-99\textsuperscript{th} percentile. Each continuous variable was analyzed using to check for mean, standard deviation, and outliers and each categorical variable was analyzed using frequency analysis to identify any outliers. Only variables with significant correlation were included in the final model to meet the linear relationship assumption. As per the assumption of normality, the error of residuals should be normally distributed, and a Shapiro-Wilk’s was created using the residual values of the dependent variable. There also should be homogeneity of variance of the residuals, meaning that the variance of residuals should be approximately equal for all predicted dependent variable values. To check for homoscedasticity, a residual plot was created and it was observed that the variance was constant across different levels of the dependent variable. Finally, multicollinearity was checked by observing the collinearity diagnostics. The term collinearity implies that two variables are near perfect linear combinations of one another. When more than two variables are involved it is often called multicollinearity. The primary concern surrounding multicollinearity is that as the degree of multicollinearity increases, the regression model estimates of the coefficients become unstable and the standard errors for the coefficients can be extremely inflated. Multicollinearity was tested to ensure that variables were measuring
different tolerance statistics. A tolerance value of 0.1 and higher was considered to be acceptable.

**Research objective 4**

*To determine the relationship between coordination of care and ease of obtaining a referral, access to care, adequacy of insurance, unmet needs, quality of healthcare interactions, severity of disease*

Logistic regression analysis was conducted to determine the predictors of having sufficient help with coordination of care among families of children with ASD. The dependent variable was sufficient help with coordination and the event selected was 1 to model the probability of having sufficient help with coordination of care. The independent variables in the analysis were adequacy of insurance, unmet needs, delaying or going without care, quality of healthcare interactions, ease of obtaining a referral, and the total SCQ score. Dummy variables were used for variables with more than two levels. The assumptions of linear relationship, normality of residuals, and homoscedasticity do not apply and hence were not included in the analysis. Multi-collinearity was assessed using the convergence criterion.
CHAPTER FOUR – RESULTS

Descriptive analysis

The dataset for access to care included 383 participants. The final dataset based on the inclusion/exclusion criteria, consisted of responses from 323 participants collected during the years 2009-10. The sample consisted of 82% males and 90% Caucasians. A detailed summary of demographic variables is described in Table 1.
Table 1: Demographic characteristics of the population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years, Mean ± SD)</td>
<td></td>
<td>9.88 ± 3.77</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>264 (81.7)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>59 (18.3)</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>293 (90.7)</td>
</tr>
<tr>
<td></td>
<td>African American</td>
<td>14 (4.3)</td>
</tr>
<tr>
<td></td>
<td>Pacific Islander</td>
<td>2 (0.6)</td>
</tr>
<tr>
<td></td>
<td>American Indian or Alaskan</td>
<td>5 (1.5)</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
<td>8 (2.5)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>11 (3.4)</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
<td>2 (0.6)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Hispanic</td>
<td>23 (7.1)</td>
</tr>
<tr>
<td></td>
<td>Non-Hispanic</td>
<td>300 (92.9)</td>
</tr>
<tr>
<td>Total household income</td>
<td>&lt; $10,000</td>
<td>11 (3.5)</td>
</tr>
<tr>
<td></td>
<td>$10,000-39,999</td>
<td>58 (18.7)</td>
</tr>
<tr>
<td></td>
<td>$40,000-69,999</td>
<td>69 (22.3)</td>
</tr>
<tr>
<td></td>
<td>$70,000-99,999</td>
<td>70 (22.6)</td>
</tr>
<tr>
<td></td>
<td>&gt; $100,000</td>
<td>102 (32.9)</td>
</tr>
<tr>
<td>Co-morbidities</td>
<td>Motor delay</td>
<td>148 (45.8)</td>
</tr>
<tr>
<td></td>
<td>ADHD</td>
<td>101 (31.2)</td>
</tr>
<tr>
<td></td>
<td>Anxiety disorder</td>
<td>57 (17.6)</td>
</tr>
<tr>
<td></td>
<td>Mental retardation</td>
<td>27 (8.4)</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>24 (7.4)</td>
</tr>
<tr>
<td></td>
<td>Seizures/epilepsy</td>
<td>19 (5.9)</td>
</tr>
<tr>
<td></td>
<td>Bipolar disorder</td>
<td>11 (3.4)</td>
</tr>
<tr>
<td></td>
<td>Cerebral palsy</td>
<td>5 (1.7)</td>
</tr>
<tr>
<td>Insurance coverage</td>
<td>Yes</td>
<td>316 (97.8)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7 (2.2)</td>
</tr>
<tr>
<td>SCQ total score (Mean ± SD)</td>
<td></td>
<td>22.21 ± 6.57</td>
</tr>
<tr>
<td>SRS total score (Mean ± SD)</td>
<td></td>
<td>104.14 ± 29.43</td>
</tr>
</tbody>
</table>

n = Number of individuals; SD = Standard deviation; SCQ: Social communication questionnaire; SRS: Social Responsiveness Scale

The unmet healthcare needs among children and parents of children with ASD are reported in Table 2. The most important unmet need was the adequacy of child’s health
insurance, with nearly 58% parents indicating that the child’s insurance never or sometimes covered services that the child needed. Thirty five percent of parents indicated needing but not receiving behavioral health services. In addition, approximately 30% of parents indicated having unmet needs related to physical/occupational therapy (Table 2).

Table 2: Healthcare and insurance needs

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmet needs</td>
<td>Behavioral therapy</td>
<td>114 (35.4)</td>
</tr>
<tr>
<td></td>
<td>Speech therapy</td>
<td>100 (31.1)</td>
</tr>
<tr>
<td></td>
<td>Physical/occupational therapy</td>
<td>96 (29.7)</td>
</tr>
<tr>
<td></td>
<td>Family mental health</td>
<td>86 (26.6)</td>
</tr>
<tr>
<td></td>
<td>Respite care</td>
<td>84 (26)</td>
</tr>
<tr>
<td></td>
<td>Specialty care</td>
<td>64 (19.8)</td>
</tr>
<tr>
<td></td>
<td>Mental health</td>
<td>54 (16.8)</td>
</tr>
<tr>
<td></td>
<td>Genetic counselling</td>
<td>43 (13.3)</td>
</tr>
<tr>
<td></td>
<td>Communication devices</td>
<td>32 (9.9)</td>
</tr>
<tr>
<td></td>
<td>Supplies</td>
<td>23 (7.1)</td>
</tr>
<tr>
<td></td>
<td>Prescription medicine</td>
<td>13 (4)</td>
</tr>
<tr>
<td>Insurance meets needs</td>
<td>Never</td>
<td>32 (9.9)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>154 (47.7)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>100 (31)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>37 (11.5)</td>
</tr>
</tbody>
</table>

n = Number of individuals

Another important concept that was the focus of this study was the parent-perceived quality of healthcare interactions as reported in Table 3. The aspects of quality of healthcare interactions included: providers spent enough time at appointments, listened to the parents, made sure parents felt like partners in the child’s healthcare decision, were sensitive to the parents, and provided all the necessary information to the parents. In addition, owing to the large number of services needed by the child, how often parents received help with coordinating care of the child was also studied. Although quality of
healthcare interactions was found to be acceptable for most children with ASD, a large proportion of parents indicated that doctors were unable to provide adequate level of care in 20-42% of the cases. A majority of parents (61%) indicated that the frequency of help with coordination was low or absent and the healthcare providers’ ability to offer useful and 42% parents indicated that doctors rarely offered useful information (See Table 3 for more details).
Table 3: Quality of healthcare interactions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Frequency n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor spends appropriate time at appointments</td>
<td>Never</td>
<td>8 (2.5)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>94 (29.1)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>124 (38.4)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>97 (30)</td>
</tr>
<tr>
<td>Doctor listens to complains</td>
<td>Never</td>
<td>2 (0.6)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>67 (20.7)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>137 (42.4)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>117 (36.2)</td>
</tr>
<tr>
<td>Doctor sensitive to families’ values</td>
<td>Never</td>
<td>12 (3.7)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>43 (13.4)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>131 (40.8)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>135 (42.0)</td>
</tr>
<tr>
<td>Doctor provides useful information</td>
<td>Never</td>
<td>41 (12.7)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>94 (29.1)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>120 (37.1)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>68 (21.1)</td>
</tr>
<tr>
<td>Doctor treats parent like a partner in child’s care</td>
<td>Never</td>
<td>14 (4.3)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>65 (20.1)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>119 (36.8)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>125 (38.7)</td>
</tr>
<tr>
<td>Coordination of care</td>
<td>Never</td>
<td>139 (43.2)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>58 (18)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>59 (18.3)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>66 (20.5)</td>
</tr>
</tbody>
</table>

n = Number of individuals

Research objective 1

To determine the economic impact of ASD on the families of children with ASD

Among parents of children with ASD, over 40% indicated having financial problems because of child’s health. This was found to be applicable across all levels of income, with 43% of parents belonging to a household with total household income greater than $100,000 indicating financial problems because of the child’s health. The proportion of
parents who indicated having financial problem because of child’s health was highest in the income range of $10,000-70,000, ranging from slightly over half to approximately two-thirds (Table 4)

Table 4: Financial problems by level of total household income

<table>
<thead>
<tr>
<th>Level</th>
<th>Financial problems n (%)</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total household income</td>
<td>&lt; $10,000</td>
<td>6 (54.6)</td>
<td>5 (45.4)</td>
</tr>
<tr>
<td></td>
<td>$10,000-39,999</td>
<td>38 (65.5)</td>
<td>20 (34.5)</td>
</tr>
<tr>
<td></td>
<td>$40,000-69,999</td>
<td>45 (65.2)</td>
<td>24 (34.8)</td>
</tr>
<tr>
<td></td>
<td>$70,000-99,999</td>
<td>37 (52.9)</td>
<td>33 (47.1)</td>
</tr>
<tr>
<td></td>
<td>&gt; $100,000</td>
<td>44 (43.1)</td>
<td>58 (56.9)</td>
</tr>
</tbody>
</table>

n = Number of individuals

Having children with ASD also hindered parental participation in the workforce, with 78% indicating they had to make changes to their work status to accommodate for their child’s needs. A total of 37% stopped working and 41% reduced hours of working (Table 5).
### Table 5: Economic impact on family

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Frequency</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family reduced working hours</td>
<td>Yes</td>
<td>132</td>
<td>41</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family stopped working</td>
<td>Yes</td>
<td>120</td>
<td>37</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Need more income</td>
<td>Yes</td>
<td>158</td>
<td>49</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial problems because of child’s health</td>
<td>Yes</td>
<td>173</td>
<td>53.6</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Out of pocket payment</td>
<td>Nothing</td>
<td>18</td>
<td>5.6</td>
</tr>
<tr>
<td></td>
<td>&lt; $250</td>
<td>40</td>
<td>12.4</td>
</tr>
<tr>
<td></td>
<td>$250-499</td>
<td>47</td>
<td>14.5</td>
</tr>
<tr>
<td></td>
<td>$500-999</td>
<td>44</td>
<td>13.6</td>
</tr>
<tr>
<td></td>
<td>$1,000-4,999</td>
<td>109</td>
<td>33.8</td>
</tr>
<tr>
<td></td>
<td>≥ $5,000</td>
<td>65</td>
<td>20.1</td>
</tr>
</tbody>
</table>

n = Number of individuals

Analysis of the patients’ health insurance showed that the majority of patients (80%) were insured by one type of insurance and a few patients (18%) had simultaneous coverage by two types of insurances. The most common type of insurance was employer-provided health insurance (76%) and the second highest insurance provider was Medicaid with insurance provision to 31% children with ASD. Other types of insurances that children were covered under include Children’s Health Insurance Program and Military Health Plan. Overall, 55% of children with ASD never or sometimes had adequate insurance. The proportion was higher among privately insured patients with 60% indicating never or sometimes having adequate insurance and 45% patients insured by Medicaid indicating never or sometimes having adequate insurance.
A chi-square test was conducted to analyze the difference in adequacy of insurance based on whether or not a person had private insurance and whether or not a person was covered by Medicaid. The results of the chi-square test demonstrated that adequacy of insurance showed a statistically significant difference based on the presence or absence of private insurance coverage ($p = 0.0068$) and the presence or absence of Medicaid coverage ($p = 0.0158$). A greater proportion of children covered by Medicaid had adequate insurance at most times (54%) as compared to children covered by private insurance (40%). Statistically significant differences were observed in out-of-pocket payments based on the presence or absence of private insurance coverage ($p < 0.001$) and the presence of absence of Medicaid coverage ($p = 0.0006$). A greater proportion (62%)
of children with Medicaid coverage had out-of-pocket costs under $1000 as compared to children with private coverage (38%).

Research objective 2

To determine the relationship between financial burden among families of children with ASD and coordination of care, unmet needs, access to care, quality of health interactions, adequacy of insurance

The logistic regression analysis showed that the model successfully predicted financial burden among families of children with ASD (p < 0.0001) explaining 21% of variance for quality of health interactions. The analysis of maximum likelihood estimates showed that adequacy of insurance (p = 0.0009), number of unmet needs (p = 0.0005), and having insufficient help with coordination (p < 0.0001) were significant predictors of having financial problems. Having ‘adequate insurance’ sometimes was associated with a 4.6 times higher likelihood of having financial problem as compared to ‘having adequate insurance’ always. Every unit increase in the number of unmet needs was associated with 30% increased likelihood of experiencing financial burden. Patients having insufficient help with coordination of healthcare were 2.8 times more likely to have financial problems as compared to patients having sufficient help with coordination of healthcare. The detailed results are presented in Table 6.
Table 6: Predictors of quality of financial burden

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Level</th>
<th>B</th>
<th>SE</th>
<th>Wald Chi-Square</th>
<th>P</th>
<th>OR (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td></td>
<td>-1.15</td>
<td>0.72</td>
<td>0.25</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Adequacy of insurance</td>
<td>Never</td>
<td>0.33</td>
<td>0.32</td>
<td>1.08</td>
<td>0.29</td>
<td>3.2 (1.2-10.0)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.69</td>
<td>0.21</td>
<td>11.04</td>
<td>&lt;0.01***</td>
<td>4.7 (1.9-11.4)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>-0.17</td>
<td>0.22</td>
<td>0.56</td>
<td>0.45</td>
<td>2.0 (0.8-4.9)</td>
</tr>
<tr>
<td></td>
<td>Always †</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmet needs</td>
<td></td>
<td>0.26</td>
<td>0.08</td>
<td>12.077</td>
<td>&lt;0.01***</td>
<td>1.3 (1.1-1.5)</td>
</tr>
<tr>
<td>Going without care/delaying care</td>
<td>No</td>
<td>-0.06</td>
<td>0.33</td>
<td>0.15</td>
<td>0.70</td>
<td>0.9 (0.5-1.7)</td>
</tr>
<tr>
<td></td>
<td>Yes †</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of healthcare interactions</td>
<td></td>
<td>0.05</td>
<td>0.04</td>
<td>1.14</td>
<td>0.28</td>
<td>1.0 (0.9-1.1)</td>
</tr>
<tr>
<td>Sufficient help with coordination of care</td>
<td>No</td>
<td>0.52</td>
<td>0.30</td>
<td>11.99</td>
<td>&lt;0.01***</td>
<td>2.8 (1.5-5.1)</td>
</tr>
<tr>
<td></td>
<td>Yes †</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*B = parameter estimate; CI = confidence interval; OR = odds ratio; p = probability; SE = standard error; **statistically significant at *p <0.001*; Dependent variable: Financial burden; *R² = 0.2108; p <0.01*
Research objective 3

To determine the relationship between quality of healthcare interactions and access to care, adequacy of insurance, unmet needs, coordination of care, severity of disease

Internal consistency of quality of health interactions scale

The quality of health interactions scale showed a strong internal consistency i.e. standardized $\alpha > 0.85$. This means that all questions designed to pertain to quality of health interactions were sufficiently correlated with the remaining questions pertaining to quality of health interactions.

Table 7: Cronbach's coefficient alpha - quality of health interactions scale

<table>
<thead>
<tr>
<th>Variables</th>
<th>Alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Raw</td>
<td>0.89</td>
</tr>
<tr>
<td>Standardized</td>
<td>0.89</td>
</tr>
</tbody>
</table>

Multicollinearity diagnostics for quality of health interactions scale

As seen in Table 8, below tolerance was not found to be an issue as most tolerance values were found to be $> 0.1$. The value of tolerance statistics for the ‘Always’ category of each variable was found to be low. However, this is a common phenomenon when using categorical variables with three or more categories even if the variable is not associated with other variables. This does not have an impact on the overall regression and was therefore determined to be acceptable.
### Table 8: Multi-collinearity - Quality of health interactions scale

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor spends appropriate time at appointments</td>
<td>Never</td>
<td>0.66</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.30</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.47</td>
</tr>
<tr>
<td></td>
<td>Always†</td>
<td>0</td>
</tr>
<tr>
<td>Doctor listens to complains</td>
<td>Never</td>
<td>0.75</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.29</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.41</td>
</tr>
<tr>
<td></td>
<td>Always†</td>
<td>0</td>
</tr>
<tr>
<td>Doctor sensitive to families’ values</td>
<td>Never</td>
<td>0.61</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.44</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.54</td>
</tr>
<tr>
<td></td>
<td>Always†</td>
<td>0</td>
</tr>
<tr>
<td>Doctor provides useful information</td>
<td>Never</td>
<td>0.42</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.34</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.45</td>
</tr>
<tr>
<td></td>
<td>Always†</td>
<td>0</td>
</tr>
<tr>
<td>Doctor treats parent like a partner in child’s care</td>
<td>Never</td>
<td>0.51</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.31</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.45</td>
</tr>
<tr>
<td></td>
<td>Always†</td>
<td>0</td>
</tr>
</tbody>
</table>

†Reference category

The results of the internal consistency and multi-collinearity together indicate that the quality of care scale was found to have strong internal consistency without redundancy. Thus, the variable was appropriate for usage in further analysis.

**Regression analysis to determine predictors of quality of health interactions**

The aim of the regression analysis was to determine the predictors of quality of health interactions among children with ASD. The following regression model was tested.
For the results of a multiple regression analysis to be valid, a number of assumptions must be met:

- **Linear relationship between dependent and independent variables:** The variables that had a significant correlation were access to care, adequacy of insurance, unmet needs, help with coordination, SRS total score and total scores for all SRS domains (Table 9). The SCQ total score and total score for all SCQ domains did not have a linear relationship with quality of health interactions. Only variables with significant correlation were included in the final model to meet the linear relationship assumption.
Table 9: Correlation analysis for all possible independent variables vs. Quality of healthcare interactions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pearson Correlation Coefficient</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed or no care</td>
<td>-0.37</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Adequacy of insurance</td>
<td>0.32</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Unmet needs</td>
<td>-0.45</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Sufficient coordination</td>
<td>0.46</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>SCQ total</td>
<td>-0.07</td>
<td>0.21</td>
</tr>
<tr>
<td>Communication domain score</td>
<td>-0.004</td>
<td>0.93</td>
</tr>
<tr>
<td>Behavior domain score</td>
<td>0.009</td>
<td>0.87</td>
</tr>
<tr>
<td>SRS total score</td>
<td>-0.20</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>SRS t-score</td>
<td>-0.20</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Social communication t-score</td>
<td>-0.22</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Social cognition t-score</td>
<td>-0.19</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Social motivation t-score</td>
<td>-0.20</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Autistic mannerisms t-score</td>
<td>-0.12</td>
<td>0.02*</td>
</tr>
<tr>
<td>Awareness t-score</td>
<td>-0.15</td>
<td>&lt;0.01*</td>
</tr>
</tbody>
</table>

*Significant at p < 0.05

- **Error (residuals) should be normally distributed:** Many common tests of null hypotheses on regression results require normality. The data were found to meet the assumption of normality as $p = 0.0149$ (i.e. $p < 0.05$) through the Shapiro Wilk’s test (Table 10)
Table 10: Tests for normality - quality of care regression analysis

<table>
<thead>
<tr>
<th>Test</th>
<th>Statistic</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shapiro-Wilk</td>
<td>0.98</td>
<td>0.01</td>
</tr>
</tbody>
</table>

- **Homoscedasticity:** No obvious patterns were observed (Figure 6) Hence, no heteroscedasticity was identified and assumption of homoscedasticity was met

Figure 6: Residual vs. predicted values for quality of care regression analysis

- **Multicollinearity:** The tolerance statistic for all variables was found to be $> 0.1$ and hence the multicollinearity was not an issue with the analysis (Table 11). The tolerance statistic was $< 0.1$ only for a level of adequacy of insurance. Again, this occurs with categorical variables with more than three levels.
### Table 11: Multi-collinearity diagnostics for independent variables used to predict quality of healthcare interactions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td></td>
<td>5.4</td>
</tr>
<tr>
<td>Going without care/delaying care</td>
<td></td>
<td>0.75</td>
</tr>
<tr>
<td>Adequacy of insurance</td>
<td>Never</td>
<td>0.56</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>0.35</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>0.39</td>
</tr>
<tr>
<td></td>
<td>Always¹</td>
<td></td>
</tr>
<tr>
<td>Unmet needs</td>
<td></td>
<td>0.58</td>
</tr>
<tr>
<td>Sufficient co-ordination</td>
<td></td>
<td>0.78</td>
</tr>
<tr>
<td>Social cognition t-score</td>
<td></td>
<td>0.35</td>
</tr>
<tr>
<td>Social motivation t-score</td>
<td></td>
<td>0.57</td>
</tr>
<tr>
<td>Autistic mannerism score</td>
<td></td>
<td>0.38</td>
</tr>
<tr>
<td>Awareness t-score</td>
<td></td>
<td>0.47</td>
</tr>
</tbody>
</table>

¹Reference category

The model was found to significantly predict quality of health interactions ($p < 0.0001$) explaining 36% of variance for quality of health interactions (Table 12). The significant predictors of quality of health interactions were access to care, adequacy of insurance, unmet needs, sufficient coordination, and social motivation t-score ($p < 0.05$).
### Table 12: Predictors of quality of healthcare interactions

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>B</th>
<th>SE</th>
<th>CI Lower bound</th>
<th>CI Upper bound</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Going without care / Delaying care</td>
<td>No</td>
<td>1.37</td>
<td>0.41</td>
<td>0.58</td>
<td>2.17</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequacy of insurance</td>
<td>Never</td>
<td>-2.00</td>
<td>0.71</td>
<td>-3.40</td>
<td>-0.59</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>-1.53</td>
<td>0.54</td>
<td>-2.60</td>
<td>-0.46</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>-0.80</td>
<td>0.56</td>
<td>-1.90</td>
<td>0.29</td>
<td>0.15</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient coordination of care</td>
<td>No</td>
<td>-2.20</td>
<td>0.37</td>
<td>-2.92</td>
<td>-1.47</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmet needs</td>
<td></td>
<td>-0.30</td>
<td>0.09</td>
<td>-0.48</td>
<td>-0.11</td>
<td>&lt;0.01*</td>
</tr>
<tr>
<td>Social cognition t-score</td>
<td></td>
<td>-0.02</td>
<td>0.02</td>
<td>-0.06</td>
<td>0.02</td>
<td>0.38</td>
</tr>
<tr>
<td>Social motivation t-score</td>
<td></td>
<td>-0.03</td>
<td>0.01</td>
<td>-0.06</td>
<td>-0.004</td>
<td>0.02*</td>
</tr>
<tr>
<td>Awareness t-score</td>
<td></td>
<td>0.01</td>
<td>0.02</td>
<td>-0.02</td>
<td>0.05</td>
<td>0.09</td>
</tr>
<tr>
<td>Autistic mannerisms domain score</td>
<td></td>
<td>0.02</td>
<td>0.01</td>
<td>0.00</td>
<td>0.05</td>
<td>0.01**</td>
</tr>
</tbody>
</table>

*B = Parameter estimate; CI = Confidence interval; p = probability; \(R^2\) = variance; SE = Standard Error;  
*Statistically significant at \(p < 0.05\); **Statistically significant at \(p < 0.01\); ***Statistically significant at \(p < 0.001\);  
Dependent variable: Quality of healthcare interactions \((p < 0.01***)\); \(R^2 = 0.3629\)
Research objective 4

To determine the relationship between coordination of care and ease of obtaining a referral, access to care, adequacy of insurance, unmet needs, quality of healthcare interactions, severity of disease

The logistic regression analysis showed that the model was successful in the prediction of sufficient coordination (p < 0.0001) explaining 31% of variance for quality of health interactions. The analysis of maximum likelihood estimates showed that ease of obtaining referral (p = 0.0002), number of unmet needs (p < 0.0001), and quality of care (p < 0.0001) were significant predictors of having sufficient help with coordination of care. Having ease of referral was associated with a four times higher likelihood of sufficient help with coordination. Every unit increase in the number of unmet needs was associated with 30% lower likelihood of having sufficient help with coordination. Every unit increase in quality of care was associated with a 30% greater likelihood of having sufficient help with coordination. (See Table 13 for more details).
Table 13: Predictors of care co-ordination

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Level</th>
<th>B</th>
<th>SE</th>
<th>Wald Chi-Square</th>
<th>P</th>
<th>OR (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td></td>
<td>-3.59</td>
<td>0.92</td>
<td>15.20</td>
<td>&lt;0.01***</td>
<td></td>
</tr>
<tr>
<td>Ease of referral</td>
<td>No</td>
<td>-0.71</td>
<td>0.19</td>
<td>13.86</td>
<td>&lt;0.01***</td>
<td>0.24 (0.1 - 0.5)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adequacy of insurance</td>
<td>Never</td>
<td>0.11</td>
<td>0.37</td>
<td>0.08</td>
<td>0.77</td>
<td>0.9 (0.2 - 3.6)</td>
</tr>
<tr>
<td></td>
<td>Sometimes</td>
<td>-0.20</td>
<td>0.23</td>
<td>0.77</td>
<td>0.38</td>
<td>0.7 (0.2 - 1.9)</td>
</tr>
<tr>
<td></td>
<td>Usually</td>
<td>-0.08</td>
<td>0.27</td>
<td>0.09</td>
<td>0.76</td>
<td>0.8 (0.3 - 2.4)</td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Going without care / delaying care</td>
<td>No</td>
<td>-0.20</td>
<td>0.18</td>
<td>1.21</td>
<td>0.27</td>
<td>1.4 (0.7 - 2.9)</td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>Reference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unmet needs</td>
<td></td>
<td>-0.33</td>
<td>0.08</td>
<td>16.96</td>
<td>&lt;.01***</td>
<td>0.7 (0.6 - 0.8)</td>
</tr>
<tr>
<td>Total score SCQ</td>
<td></td>
<td>0.03</td>
<td>0.02</td>
<td>1.51</td>
<td>0.22</td>
<td>1.0 (0.98 - 1.1)</td>
</tr>
<tr>
<td>Quality of healthcare interactions</td>
<td></td>
<td>0.26</td>
<td>0.05</td>
<td>29.01</td>
<td>&lt;.01***</td>
<td>1.3 (1.2 - 1.4)</td>
</tr>
</tbody>
</table>

*B = Parameter estimate; CI = Confidence interval; OR = odds ratio; p = probability; Reference category; SE = Standard Error; 
***Statistically significant at p <0.001; Dependent variable: Sufficient help with coordination; $R^2 = 0.3159$; p <0.01
CHAPTER FIVE – DISCUSSION

Discussion

The first objective of the study was to explore the economic impact of ASD on families as measured by three indicators: having financial problems because of child’s ASD, having annual out-of-pocket payments greater than $1000, and having to cut back or stop working to account for child’s healthcare needs. The study demonstrated that ASD had a considerable impact on families in terms of all three outcomes: 53.6% had financial problems because of child’s ASD, 53.9% had out-of-pocket payments greater than $1,000, and 78% had to cut back hours or stop working to accommodate for their child’s healthcare needs. When compared to the national average among families of children with special healthcare needs, the proportion of families with the above-mentioned outcomes was higher among families of children with ASD. The national average for families of children with special healthcare needs were as follows: 21.6% had financial problems because of the child’s health, 22.1% had annual out-of-pocket payments greater than $1,000, and 25% had to cut back hours or stop working to accommodate for their child’s needs. Further exploration of the data demonstrated that having financial burden was attributable to having inadequate insurance coverage, but not to the total household income. The results were consistent to those observed by another study, which reported that greater proportion of families of children with ASD had financial burden as compared to families of children with developmental disabilities such as cerebral palsy, Down syndrome, developmental delay, or intellectual disability. As per the study, families of children with ASD were 45% more likely to have financial burden as compared to families of children with developmental disabilities.
This study also found that, out-of-pocket payments differed significantly based on type of insurance, with out-of-pocket costs less than $1000 for 62% families of children with Medicaid coverage and out-of-pocket costs less than $1000 for 38% families of children with private insurance coverage. The findings were corroborated by another study, which demonstrated that the median annual out-of-pocket cost among low-income families (at 200% federal poverty line) was higher for children who had private insurance coverage ($623) vs. children who were insured by Medicaid/S-CHIP ($287). Although causality of this effect was not analyzed in this study, the effect may be attributable in part to the lower co-payments and better coverage of services provided by Medicaid as compared to private insurance. In the current study, 54% of children covered by Medicaid were offered benefits that met the child’s needs most of the time as compared to 40% of children covered by private insurance. Another study has shown that many of the services recommended for children with ASD are often excluded under private plans because they are unproven or experimental. The most significant finding of the current study with respect to health insurance is that despite having insurance children with ASD continue to be at a risk of being underinsured; although majority of children (97.8%) were covered by some kind of insurance, a limited proportion (11.5%) found the insurance to be adequate, including those covered by Medicaid. The study highlights that it may be necessary to institute additional provisions for children with ASD to obtain necessary services.

The second objective of the study was to identify aspects of the healthcare systems that may be associated with financial burden on families of children with ASD. As expected,
inadequacy of insurance was a significant predictor of financial burden. Children who had adequate insurance coverage usually were less likely to have financial burden because of child’s health compared to those who had adequate insurance coverage only sometimes. In addition, this study identified the number of unmet needs and insufficient care coordination as significant predictors of financial burden. The results of this study demonstrate that provision of coordinated care may help reduce financial burden on the families, most likely due to the reduced use of inappropriate and costly healthcare services. The variable unmet healthcare needs was a proxy variable for measuring difficulties with healthcare access. It is noteworthy that having difficulty with access to healthcare predicted financial burden beyond that accounted for by inadequacy of insurance coverage. While the reasons for this effect were not studied, it is speculated that this may be attributable to the shortage of healthcare professionals with sufficient qualifications to treat children with ASD.  

Due to the shortage of healthcare professionals, caregivers often have to travel far to access services. This may likely have an impact on financial burden both directly and indirectly, through lost work productivity. In the past, studies have focused on the impact of health insurance on financial burden, however, the impact of access issues beyond health insurance on financial burden have not received as much attention. This study takes into account both insurance as well as other access issues for the prediction of financial burden. While the economic benefits of coordinated care from a payer’s perspective are well-established, their financial impact on the families of children with ASD have rarely been studied. This study advocates for the adoption of coordinated and comprehensive care, which is...
akin to the medical home approach, as a possible means to help reduce financial burden.104

The next objective was to identify the relationship between parent-perceived quality of healthcare interactions and other aspects of the healthcare system. As documented in other studies, this study found that a large proportion of patients perceived quality of healthcare interactions to be acceptable sometimes or never.92 Although studies have focused on the measuring level of satisfaction with healthcare interactions91,92, the factors that predict satisfaction are not well understood. This study aims to test a model for the prediction of quality of healthcare, based on the incorporating different aspects of the healthcare systems and symptom severity. The model proposed by this study was a good predictor of quality of healthcare interactions, predicting 36% variance in quality of healthcare interactions. The results of this study imply that parents perceived the quality of healthcare interactions to be better when the child received coordinated care, were able to access needed services, and had health insurance to cover those services usually. As described previously, this was aligned with the principles of a medical home approach to treatment. Thus, based on this study, the adoption of a medical home approach may not only reduce family financial burden but also improve parental perceptions of quality of healthcare interactions, possibly reducing caregiver burden.103 In addition, this study indicated that timeliness of care predicted of parental perceptions of quality of healthcare, implying the need for more professionals with specialized training and shorter wait times to improve quality of healthcare interactions. This is in line with the recommendations proposed by several studies, which recommended the need to provide more training to
primary health care providers, so that children with ASD receive early access to evidence-based care.\textsuperscript{105,106,107} Furthermore, this study identified that specific symptoms were associated with poor healthcare quality interactions. As per the study, having problems with social motivation (i.e. would the child rather be alone or interact with others) and autistic mannerisms (i.e. overt reliance on certain routines) were associated with lower quality of healthcare interactions. The results of this study add to existing evidence that greater symptom severity is associated with lower satisfaction with healthcare providers.\textsuperscript{92} Moreover, the study goes further to explain the specific symptoms that are associated with quality of healthcare interactions. While the reasons for this were not analyzed, the findings provide an understanding of the specific parental concerns that may need to be addressed better by physicians.

The final objective of the study was to understand the predictors of coordination of care. This study found the number of unmet needs was a significant predictor of coordination of care. This finding is consistent with that observed by another study, which reported that patients who did not have coordinated care as defined by a medical home were likely to have a higher number of unmet needs as compared to patients who had medical homes.\textsuperscript{108} Other predictors of coordinated care provision include ease of referral and quality of healthcare interactions. It is worth noting that adequacy of insurance was not a significant predictor of coordinated care, instead coordinated care was associated with factors that communicate the quality of healthcare interactions. This further highlights the need for increased focus on physician training to improve quality of healthcare interactions.\textsuperscript{94,106,107}
Limitations

The limitations of the study must be taken into account while interpreting the results of the study. First, the data were provided by the members of a web-based community (the IAN). Respondents would have required internet access to be part of the community, which may have introduced a selection bias. The study sample consisted of 90% Caucasian participants as compared to an actual nationwide proportion of 58%.3 The over-representation of subjects from the Caucasian race and higher income families reduces generalizability of the findings. The study likely underestimates the financial burden among families of children with ASD. Second, the analyses were conducted on data previously recorded in the database, whose quality may be limited by systematic or recorder bias, data coding-recoding errors, incomplete data, data quality, and confounding factors. Third, the data was cross-sectional and did not permit causal conclusions. The results prove associations alone. Moreover, the study was limited to the data was provided and may not be generalizable. Finally, there is a need to have more validated measures for access to specialized and coordinated care. Despite the limitations, the findings of the study contribute significantly to the existing literature on access to services in ASD and caregiver burden.

Study Implications

This study has important implications for a number of healthcare stakeholders. With the rising prevalence of ASD, physicians and managed care organizations are faced with the challenge of providing optimal care as well as curtailing the growing cost of providing care. This study provides various insights into the issues that affect families of children with ASD, which have important implications for a number of stakeholders.
From the physicians’ perspective, the study helps physicians understand areas of care that are most problematic from the perspective of parents of children with ASD. This can help physicians address the areas of parental concern and, in turn, streamline healthcare provision and improve outcomes among children with ASD. Primary physicians should provide coordinated care, by interacting with different professionals providing healthcare. In addition, physicians should pay special attention to alleviate concerns surrounding autism mannerisms and social motivation, as these have been identified as having an association with parent-perceived quality of healthcare interactions.

From the perspective of policymakers, this reiterates some of the issues with insurance coverage. This can help provide an understanding of the current situation and find ways to improve overall healthcare in children and families of children with ASD. Policymakers should focus on improving insurance coverage by making sure that both private and public insurances cover services needed for the treatment of ASD. The study also provided additional evidence that favors the adoption of the medical homes approach to treatment.

From the parents’ perspective, the study identifies other priorities perceived by families, which can help policymakers design strategies to tackle these issues. Based on the study, strategies that can help families are providing better insurance coverage, improving the physician knowledge of ASD treatment, or providing incentives to provide coordinated care. Furthermore, the study delineates predictors of financial burden, to help parents
make informed decisions about treatments strategies for their children such as finding physicians who provide coordinated comprehensive care or using case managers to avoid utilization of expensive services without benefit.

From the ASD researchers’ perspective, this study provides a measure of reliability for the scale quality of healthcare interactions. Quality of healthcare interactions has been identified as an important construct predicting healthcare utilization. The scale used in the study has been used in research previously. However, the scale has not been tested for reliability. This study provides evidence that the scale has good reliability and can be used in future studies.

**Future directions**

This study highlighted that a large proportion of respondents indicated that insurance coverage was inadequate. Future studies should try to identify specific services that would be beneficial to cover from the parents’ perspective. Furthermore, policies that may help provide respite to families in terms of financial burden must be evaluated.

This study highlighted the potential financial benefits of providing coordinated care. Further studies of an interventional nature are needed to ascertain this effect. While adequacy of insurance was identified to be an important factor for financial burden, the study emphasized the importance of other access issues in predicting financial burden on families of children with ASD. Future studies should focus on identifying other access-related issues such as the availability of specialized care in close proximity to the residence of the family and the means to improve quality in this respect. Studies should
also identify the means needed to improve specialized education in these areas. The study also highlights the importance of healthcare access in financial burden and consequently, caregiver burden. None of the existing instruments take into account healthcare access related issues in measuring caregiver burden. It is important to develop an instrument that does so to obtain a more accurate estimation of caregiver burden.

Conclusion

Based on this study, the following conclusion can be stated: economic impact among families of children with ASD is higher as compared to families of children with developmental disorders. Factors related to provision of healthcare were significant predictors of financial burden and coordinated care, access to care, and quality of healthcare interactions were important components of healthcare for children with ASD.
REFERENCES


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