Comparison of Personal, Health and Family Characteristics of Children With and Without Autism

Alexandra Martin BSN Honors Student

Faculty Mentor: Marjorie J. Bott, PhD, RN

University of Kansas School of Nursing

Abstract

Today it is reported that one in 88 children in the U.S. has been diagnosed with autism spectrum disorder (ASD), with rates continuing to rise. Early diagnosis and intervention are imperative, as well as a systematic way to identify characteristics of children that put them at risk for ASD as well as associated comorbidities. Few studies have examined whether the health status of the child or the type of health insurance impacts the diagnosis and intervention. The aim of this study is to examine and compare the personal (child), family, and health status characteristics of children (< 18 years) with autism with a matched sample (age and gender) of children without autism as reported in the National Health Interview Survey (NHIS): 2009. A descriptive, exploratory study with secondary analysis was performed using data from the NHIS: 2009. Frequencies, chi-square, and ANOVA were used in data analysis. In this study there was a higher proportion of children with autism residing with biological, adoptive, and step parents. The study also reveals that children with autism have a significantly ($p<.05$) higher incidence of specific comorbidities such as developmental delays, learning disabilities/ADHD, and seizures, a higher number of health care visits, as well as lower average family health status scores. Identifying characteristics that are common among children with autism will help identify other health problems associated with ASD, create a systematic way to identify potential risks, and serve as a baseline for early intervention programs.

Introduction

The Centers for Disease Control and Prevention (CDC, 2012) reports that one in 88 children in the U.S. has been diagnosed with autism spectrum disorder (ASD), and rates continue to rise (CDC, 2012). Early diagnosis and intervention are imperative, as well as a systematic way to identify characteristics that put children at risk for ASD and other comorbidities. Few studies have examined whether the health status of the child or the type of health insurance impacts the diagnosis and intervention. The overall aim of this study is to examine and compare the personal (child), family, and health status characteristics of children (< 18 years) with autism with a matched sample (age and gender) of children without autism as reported in the National Health Interview Survey (NHIS): 2009.

Andersen's Model of Health Service Utilization (1995) is used as the guiding framework for the study (See Figure 1). Anderson's theory posits that predisposing characteristics impact enabling characteristics, and enabling characteristics impact need characteristics. The review of the

literature will be based on the variables identified as part of the guiding framework. For the purpose of my study the predisposing characteristics include child and family demographics and personal characteristics. For the enabling characteristics insurance and income were included because they remain unsupported by any studies found in the literature. For the need characteristics the health status of the child and the health status of all members of the family were included, as well as the child's specific diagnoses and types of health care visits.

Figure 1. Theoretical Framework adapted from Andersen's Health Service Utilization Model

PREDISPOSING CHARACTERISTICS

Child
- Gender
- Race/Ethnicity
- Age

Family
- Race/Ethnicity
- Education
- Size
- Type
- Relationship

ENABLING CHARACTERISTICS

Family
- Health Insurance
- Income
- Poverty Status

NEED CHARACTERISTICS

Health Status
- Comorbidities
  - Developmental delay
  - Down Syndrome/ MR
  - Learning Disability/ADHD
  - Asthma
  - Seizures
  - Diarrhea/colitis
- Healthcare in the past year
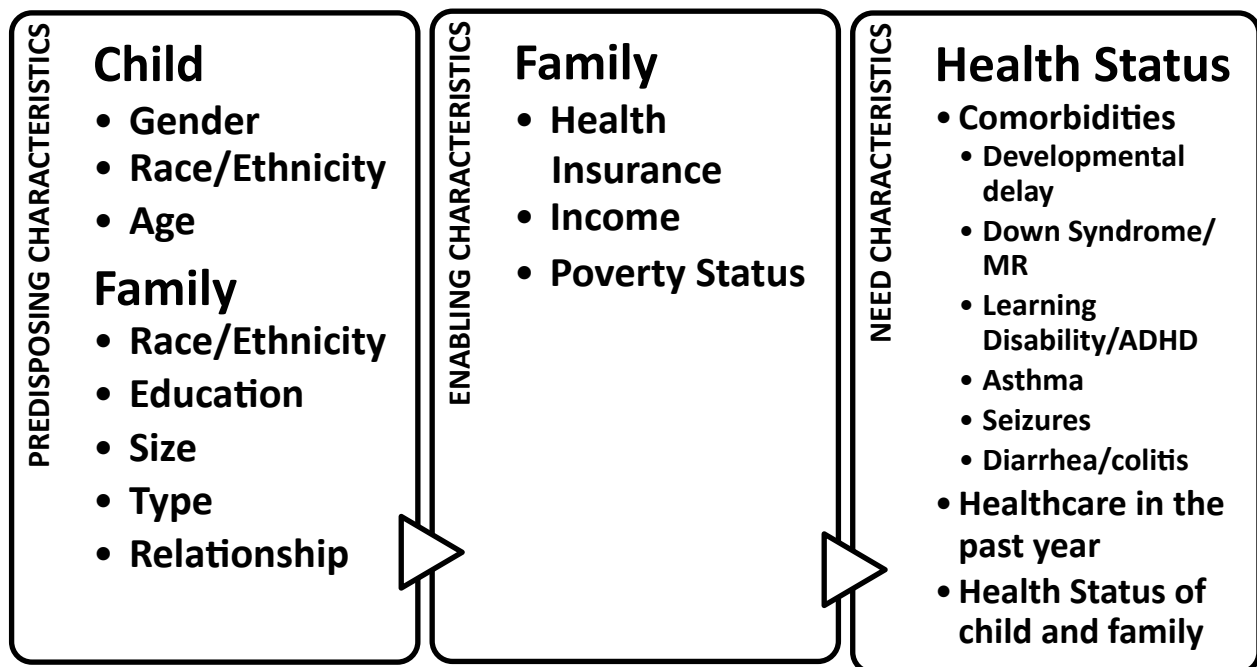- Health Status of child and family

Figure 1. The individual determinants of the Health Service Utilization Model served as a guiding framework for the study. Adapted from Revisiting the Behavioral Model and Access to Medical Care: Does it matter? Andersen R.M. (1995), *Journal of Health and Social Behavior*, 36, p 7.

Literature Review

Predisposing Characteristics

   Gender. Little is known about the specific characteristics that put children at risk for ASD. However, there have been consistent findings amongst researchers and clinicians that males are more likely than females to be diagnosed with ASD. One comprehensive review of 43 studies found the average male to female to population ratio for autism to be 4.2:1 (Fombonne, 2009). A recent study in 2012 conducted by the CDC found that the prevalence of ASD among boys is 1 in 54, making boys five times more likely than girls to have ASD. (CDC, 2012).

Race. Substantial research between the association of race and ASD is lacking. In examining the associations of ASD with socioeconomic factors, Thomas et al. (2011) found that the incidence of autism was higher among white and Asian children, than in Black and Hispanic children. However, when they controlled for income, there was no association between race and prevalence of ASD. Previously, there have been other studies that found Latino children have lower prevalence of ASD (Croen, Grether, Hoogstrate, & Selvin, 2002; Liptak et al., 2008). Mandell et al. (2009) found that later diagnosis of ASD is associated with minority race and ethnicity status.

Parental education. Rai et al. (2012) conducted a population-based study to compare demographics of children with an autism spectrum disorder (ASD) and their families compared to a matched sample of children without ASD and their families. Study findings revealed that families with lower prenatal household income and parents who held manual and unclassified occupations put children at greater risk for ASD (Rai et al., 2012). They also found no association between education of parents and diagnosis of an ASD. The conflicting and unclear results of multiple studies illustrate the need for more research to gain better insight into the effect demographics have on the diagnosis of ASD.

Enabling Characteristics

Health insurance. According to the Autism Society of America (ASA) the cost of ASD for an individual over their entire lifespan is approximately 3.2 million dollars (ASA, 2007). Health insurance coverage for the different therapies that are beneficial to children with ASD varies from state to state. Insurance coverage depends on the state's stance on the effectiveness of the therapies. For example, some states, like Pennsylvania and Arizona, have Blue Cross Blue Shield coverage for a certain therapy called applied behavioral analysis, but have a per year cap that limits how much can be spent on the therapy and specifies the ages for when coverage stops (Atlantic Information Services, 2008).

For example, in Kansas, there has been no requirement that private insurance cover any services that are used to provide autism therapies. However, a law recently passed in Kansas gives state employees coverage for ASD therapies that are deemed medically necessary. This law, however, also has a cap of $36,000 a year until age seven and $27,000 a year until age 19 (Autism Votes, 2011). Currently, the Kansas Senate is working on passing a bill that will broaden the current state employee plan that covers treatments for ASD to all state-regulated group plans (Autism Votes, 2012). Additionally in Kansas, there is an autism waiver given by Medicaid that will give needed support for families for their child to receive early, intensive intervention for autism. This

could decrease overall costs of therapies in life by two-thirds (ASA, 2007). Without insurance, children who have ASD may not be seen by a qualified health care provider and their diagnosis of ASD may not occur until years later. Early diagnosis and intervention is imperative for the success of children diagnosed with ASD and without insurance to cover early doctor visits these children may not receive necessary care for them to reach their full potential.

Income. The relationship between socioeconomic status and ASD is unclear and few studies have supported any association between the two. Thomas et al. (2011) studied the diagnosis of ASD in children and examined the correlation with median income. According to the study findings, as income increased the incidence of ASD diagnosis increased. This relationship could be attributed to children from families with higher socioeconomic status were diagnosed at an earlier age and had a higher number of evaluations. The prevalence of children with ASD with incomes < $30,000 was 7:1; for incomes $30,000 to $60,000 was 9:1; for incomes $60,000 to $90,000 was 13:4; and for incomes > $90,000 was 17:2. The investigators also found that children in families with higher income have a higher incidence of mild and severe impairment associated with ASD; however, children with moderate impairment did not follow the same trend with income (Thomas et al., 2011). These findings could lead one to think that having higher income would result in increased access to care which could play a role in diagnosis and interventions.

Need Characteristics

Comorbidities. Developmental delays in social skills, behavior, and cognitive skills are the most pronounced symptoms in children with ASD. These delays begin to appear between eighteen months and three years of age. The severity of developmental delays varies with each child, and signs and symptoms appear at different ages. Developmental delays cannot be treated pharmacologically but instead are treated by behavior therapy and educational interventions. These therapies do not cure ASD but instead help the child in the areas of speech and behavior so that they may be "mainstreamed" into schools with other children (KidsHealth, 2011).

Mental retardation is the most common comorbidity seen in children with ASD. However, the 4:2 male to female ratio declines as mental retardation increases. One study (Yeargin-Allsopp et al., 2003) found that the male to female ratios in children with ASD among three to ten year olds were 6.7:1 among children without intellectual disability; 4.4:1 in those children with IQs from 50–70, and 1.3:1 among those children with IQs less than 20 The findings reveal that as the severity of mental retardation in children with ASD increases, the likelihood of having mental retardation is just as common in females as it is in males despite males having higher incidence of ASD.

Three other comorbidities found commonly in children with ASD are epilepsy (seizures), sleep disorders (insomnia and waking in the night), and GI disorders. Epilepsy is found in about one-third of children diagnosed with ASD. In a study in California, it was found that children with autism have almost three times more chance of mortality from epilepsy than children with epilepsy without autism (Pickett et al., 2011). Sleep disorders are more common among children with ASD than normally developed children and can aggravate their autism symptoms (Siversten et al., 2011). Another study (Adams et al., 2011) found that 70% of the children with ASD had gastrointestinal (GI) issues and symptoms compared to 28% of the children with normal development. The investigator hypothesized that GI symptoms may exacerbate ASD symptoms.

Health status. No studies could be found that examined the health status characteristics of children with ASD. Similarly, no studies were found on whether there are differences between the health status of the members of families who have children with autism and those that do not. Further research is needed to see if a diagnosis of ASD results in differences in the health status of the child as well as their family members.

Research Questions

The limited research that is available on child, family, and health status of the child with ASD serves as the basis for this study. Two research questions will be explored: (a)   What are the child, family, and health status characteristics of the children with autism spectrum disorder (ASD) as reported in the National Health Interview Survey (NHIS, 2009)?; and (b) Using a stratified random sample based on age and gender, are there differences in the child, family, and health status characteristics between children with ASD and children without ASD?

Methods

This exploratory study used a secondary analysis of National Health Interview Survey (NHIS): 2009 to compare children with autism with a matched sample (age and gender) of children without autism. The NHIS is conducted annually by the National Center for Health Statistics. The interviewers visit 35,000-40,000 households across the country and collect data about 75,000-100,000 individuals (NHIS, 2011). The NHIS is a survey conducted by personal interviews that covers a wide range of health topics including information about children with autism.

Sample

From the NHIS: 2009, 112 children (< 18 years) were identified with ASD. Children without ASD (*n* =112) were randomly selected from the remaining children (*n*=10,997) and matched based on gender and age by year.

Measures

The predisposing measures that were used from the NHIS: 2009 for the child was child's *age* by year (*range* = 1-11), *gender* (male = 1; female = 2), *child/family race* (white = 1; African American = 2; American Indian/Alaskan native = 3; Asian = 4; all other races= 5); and *child/family ethnicity* (all Hispanic groups = 1; nonHispanic = 0). Other family characteristics included *family size* (the number of family members living in the household) and highest *education* of the household (less than high school =1; high school or GED = 2; some college/vocational/no degree = 3; BS or higher degree = 4). Other family characteristics that were examined were *relationship* to the child (biological/adoptive/step parents = 1; grandparent = 2; aunt/uncle = 3; brother/sister = 4; other = 5) and *family type* (single = 1; parents married or cohabitating = 2; single parent with other adult with child = 3).

The enabling measures included *income* categories ($0-$34,999 = 1; $35,000 – 74,999 = 2; $75,000 – 99,999 = 3; $100,000 or greater = 4) and *ratio of income to poverty* (less than 1.00 = 1; 1.00-1.99 = 2; 2.00-3.99 = 3; 4.00 and over = 4). *Insurance type* was operationalized into eight categories (no insurance = 0; Medicare = 1; Medicaid = 2; private insurance = 3; military coverage = 4; State/government sponsored plan = 5; Medicare/private = 6; Medicare/Medicaid = 7; Medicare/military = 8).

The need variables included *comorbidities*, *health care visits in the past year*, and *health status* of the child and family. Identified from the literature, the *comorbidities* included were developmental delay, Down's Syndrome/mental retardation, learning disability/ADHD, asthma, seizures, and diarrhea or colitis in the past year and were operationalized as yes = 1 and no = 0. *Health care visits* in the past year (yes= 1; no = 0) included well child visits to physician, nurse practitioner/physician assistant visits; mental health specialist or physician visit for emotional/behavioral problems; other physician specialist visit; emergency room/department visits; home care visits, and flu shot in past year.

The *health status* of the child (worse = -1, same =0, better = 1) and the *health status of the family* members ranged from one (poor) to five (excellent). An average was created by multiplying the number of family members who reported each response respectively from one to five, summing

the total across each response and dividing by the number of family members. The average ranged from one (poor) to five (excellent).

Data analysis

Frequency statistics using SPSS 18.0 were used to answer the first research question: What are the child, family, and health status characteristics of the children with autism spectrum disorder (ASD) as reported in the NHIS: 2009. For the second research question, *Analysis of Variance* (ANOVA) and *Chi Square* statistics were used to determine if there were differences in the child, family, and health status characteristics between children with ASD and children without ASD.

Results

There were 224 children equally divided between children with ASD and children without ASD in the matched sample obtained from the NHIS: 2009. The results for the first research question, 'what are the child, family, and health status characteristics of children with autism?' are reported in Tables 1 through 3. There is a higher incidence of ASD in males and as one would expect the majority (79%) of our sample were males, predominately white children and parents (76% and 80%, respectively), and one-fifth of the children (22%) were Hispanic. The majority (92%) of the children with autism had either a biological, adoptive or step parent report their ASD in the survey, and 56% of the children had parents who were either married or cohabitating. Approximately two-fifths (41%) of the children with ASD had parents with an education of a bachelor's degree or higher (See Table 1).

In the ASD sample, slightly more than one-third (38%) reported incomes between $35-75,000 but 28% reported incomes less than $35,000. About one-third (32%) reported incomes that were 2-3 times the poverty level and less than one-fifth (18%) reported income to poverty ratios less than 1.00. The majority of the families (60%) reported having private insurance but 17% reported they had no insurance (See table 2).

A majority of the children with ASD reported a diagnosis of developmental delay (73%) or a learning disability or ADHD (85%). Children with ASD had an average of 3.66 (range 0-8) office visits within the past year, and 79% had a well-child checkup. Within the past year, 60% of the sample had been seen by a mental health professional or physician for behavioral or emotional problems and 91% were seen by a physician specialist for comorbidities. For the health status scale of -1 (worse) to 1 (better), children with ASD reported their health status stayed about the same (M=.27). The families of children with ASD reported "good to very good" health (M=6.35) across all family members that included the child diagnosed with ASD (See Table 3).

Table 1 Predisposing Characteristics of the Child and Family Comparing Child with/without Autism

Predisposing Characteristics	Children without Autism (*n*=112)		Children with Autism (*n*=112)		Statistic
Child	*n*	*%*	*N*	*%*	*X²*
Gender (males)	88	78.6	88	78.6	NS
Hispanic	29	25.9	25	22.3	NS
Race					NS
White	75	67	85	75.9	
Black	22	19.6	18	16.1	
Indian American	1	.9	1	.9	
Asian	8	7.1	4	3.6	
Multiple Race	6	5.4	4	3.6	
	M (SD)	*Range*	*M (SD)*	*Range*	*t-test*
Age	9.62 (4.52)	1 to 17	9.63 (4.52)	1 to 17	NS
Family	*n*	*%*	*N*	*%*	*X²*
Relationship to Child					7.79
Parent-biological, adoptive, or step	95	84.8	103	92.0	*p*= .10
Grandparent	11	9.8	6	5.4	
Aunt/uncle	3	2.7	1	.9	
Brother/sister	3	2.7	2	1.8	
Family type					NS
Single parent w/ child	26	23.2	18	16.1	
Parents married or cohabitating w/ child	48	42.9	63	56.3	
Single parent w/ other adult w/child	38	33.9	31	27.7	
Parent Hispanic	30	26.8	23	20.5	NS
Parent Race					NS
White	80	71.4	89	79.5	
Black	24	21.4	17	15.2	
Asian	7	6.3	4	3.6	
All other	1	.9	2	1.8	
Highest Education of Household					NS
Less than High School	8	7.1	7	6.3	
HS or GED	27	24.1	16	14.3	
Some college, vocational, AA	44	39.3	43	38.4	
BS or higher	33	29.5	46	41.1	
	M (SD)	*Range*	*M (SD)*	*Range*	*t-test*
Family size	3.97 (1.22)	2-8	3.98 (1.32)	2-9	NS

Key: NS = Non-significant

Table 2 Enabling Characteristics of the Child and Family Comparing Child with/without Autism

Enabling Characteristics	Children without Autism (n=112)		Children with Autism (n=112)		Statistic
	n	**%**	**N**	**%**	**X^2**
Income					NS
0-34,999	30	26.8	31	27.7	
35,000-74,999	33	29.5	42	37.5	
75,000-99,999	18	16.1	12	10.7	
100,000 or greater	24	21.4	22	19.6	
Ratio of income to poverty status					NS
<1.00	17	15.2	20	17.9	
1.00-1.99	19	17.0	20	17.9	
2.00-2.99	36	32.1	36	32.1	
4.00 and over	31	27.7	27	24.1	
Insurance Type					NS
None	23	20.5	19	17.0	
Medicare	2	1.8	2	1.8	
Medicaid	12	10.7	10	8.9	
Private	70	62.5	67	59.8	
Military coverage	1	.9	2	1.8	
State sponsored/Gov.	3	2.7	8	7.1	
Medicare/private ins. /military	1	.9	1	2.7	
Medicare/Medicaid	0	0	3	.9	

Key: NS= Non-significant

Table 3 Need Characteristics of the Child and Family Comparing Child with/without Autism

Need Characteristics	Children without Autism (n=112)		Children with Autism (n=112)		Statistic
Health Status	**n**	**%**	**N**	**%**	**X²**
Diagnosis					
Developmental delay	4	3.6	82	73.2	114.83**
Down Syndrome/MR	1	.9	24	21.4	23.82**
Learning disability/ADHD					
Asthma	15	13.4	95	84.8	114.32**
Seizures	18	16.1	25	22.3	NS
Diarrhea or colitis in past	0	0	7	6.3	7.23*
year	1	.9	6	5.4	NS
Talked to Health Professional in past year					
NP/PA	1	.9	0	0	NS
Mental Health professional/MD	9	8.0	67	59.8	66.99**
MD specialist	83	74.1	102	91.1	11.21*
Health care in past year					
Well-child checkup	87	77.7	88	78.6	NS
ER/ED visit	16	14.3	27	24.1	NS
Home Care	0	0	10	8.9	10.47*
Flu shot	33	29.5	37	33.0	NS
	M	*Range*	*M (SD)*	*Range*	*t-test*
Number of office visits in past year	2.06 (1.45)	0 to 7	3.66 (2.55)	0 to 8	5.78**
Child health status in past year (response options: -1=worse, 0=same, 1=better)	.16 (.42)	-1 to 1	.27 (.50)	-1 to 1	1.74 p = .08
Average family health status score (response options: (1=poor health, 2=fair health, 3=good health, 4=very good health, 5=excellent health)	4.16 (.79)	2.33-5	3.65 (.79)	1-5	4.2**

Key: **p<.001; *p<.01; NS= Non-significant

For the second research question, the differences between children with autism and a matched sample of children without autism were explored. Primarily there were no significant (p<.05) differences between groups among the predisposing child or family characteristics (e.g. race, parent race, family type, and highest education of household). Although not significant (p=.10), there was a higher proportion of children with autism whose biological, adoptive, or step parent were the primary interviewee (See Table 1). For the enabling characteristics, there were no

significant (p<.05) differences between the two groups on income, income/poverty ratio, or insurance type (See Table 2).

For the need characteristics shown in Table 3, children with autism reported a significantly higher incidence of diagnosis of developmental delay (p<.001), Down Syndrome/mental retardation (p<.001), learning disabilities/ADHD (p<.001), and seizures (p<.01). Children with autism also reported a significantly higher number of visits to MD and Mental Health professionals for emotional or behavioral problems (p<.001), physician specialist for other comorbidities (p<.01), and home care visits (p<.01). Children with autism had on average 1.66 more office visits per year than children without autism. The average health status for the families of children with autism was significantly lower (M=3.65) than families of children without autism (M=4.16). Children with autism reported a slightly higher but insignificant health status than children without autism (See Table 3).

Discussions and Conclusions

Although there were no significant differences amongst the chosen predisposing characteristics, the trend toward more children with autism being reported by biological, adoptive, or step parents was an unexpected finding. This could be attributed to the notion that parents are more "in tune" to their child's behavior and perhaps notice ASD symptoms more quickly. Previous studies have not reported significant associations between socioeconomic status and diagnosis of ASD, which is similar to the findings in this study.

Findings from this study showed the majority of the sample had private insurance. However, what cannot be ascertained from the data collected in the NHIS is if the private insurance provides coverage for the costly treatments required for children with ASD. There were several significant differences for the incidence of comorbidities between the children with and without ASD. Other studies, such as the one conducted by Siversten et al. (2011), suggested that sleep disorders such as insomnia and waking in the night are prevalent among children with ASD. Because the NHIS did not collect data on sleep disorders, it was not possible to explore this in this study.

Even though only a small percentage (6%) of children with ASD reported having seizures, no children from the sample of children without ASD reported any seizure activity. However, this may be a sampling issue as only 1% of the total number of children without autism in the NHIS reported seizure activity. Findings about the increased incidence of developmental delays and

learning disabilities are not surprising given that ASD is often associated with intellectual disabilities and difficulties in motor coordination.

As expected children with ASD had more visits to see a mental health professional or physician for emotional and behavioral problems. Given that ASD is characterized by varying difficulties in social interaction, verbal and nonverbal communication, and repetitive behaviors as defined by Autism Speaks (2005-2012), it would be expected that they would have more mental health professional visits. In the past year, children with autism made, on average, about one and one half more visits to their physician's office than children without ASD, which may not be surprising given their accompanying comorbidities.

Results like these are important for health care professionals to know because as the incidence of ASD rises, more and more of these children will be seen in our clinics and hospitals. It is important for health care professionals to know the signs and symptoms of ASD so that they may work toward a diagnosis and begin the imperative early intervention programs for the child. It also is important for the health care providers to be knowledgeable about other diagnoses associated with ASD and other common features in order to intervene early and prevent complications from the comorbidities. Knowing families with a child diagnosed with ASD may experience changes to their own health that lowers their general health status will help the health care professionals give more holistic and family-based care that could benefit the family and the child. More research is needed to address the issues surrounding the health status of the child with autism and the health status of their families.

The study findings helped identify other health problems associated with ASD. The findings from this study could, in the future, help to provide direction to identify characteristics specific for autism that will help create a systematic way to identify potential risks for autism and corresponding comorbidities. It also may serve as a baseline for early intervention for health problems associated with ASD.

Limitations

Limitations to this study are that the small sample of children with autism in the NHIS: 2009 may not be representative of the population. The number of children with ASD was one in 102 in this sample that is a lower rate when compared to the current estimates by the CDC, (2012). Additionally, a secondary analysis does not include all variables, such as sleep disorders and specific insurance coverage benefits that are necessary for risk identification.

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