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Children with Autism Spectrum Disorders: An Investigative Analysis of their Access to Dental Care

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CHILDREN WITH AUTISM SPECTRUM DISORDERS: AN INVESTIGATIVE ANALYSIS OF THEIR ACCESS TO DENTAL CARE

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

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Abstract

CHILDREN WITH AUTISM SPECTRUM DISORDERS: AN INVESTIGATIVE ANALYSIS OF THEIR ACCESS TO DENTAL CARE

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Major Director: Frank H. Farrington, D.D.S., M.S.
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Purpose: The purpose of this study was to assess the utilization of dental services for children with autism spectrum disorders and identify barriers these children face when accessing dental services in the state of Virginia.

Methods: A survey was mailed to families in the state of Virginia that care for at least one child with the neuro-developmental disorder on the autism spectrum scale. The mailing list was obtained from "The Autism Program of Virginia." This list contains the names of families/guardians of children with autism spectrum disorders. These individuals live throughout the State of Virginia. This project analyzed survey questions directly related to

dental care access issues and other socioeconomic factors (age, race, family, income, sex and parental education).

Results: The response rate of the survey was 29%. Autism was the most common diagnosis of the autism spectrum disorders among respondent's children (60%). No significant difference was found however, between access to dental services and the child's diagnosis. The majority of the children were white males between the ages of 3-11 years old. A history of difficult behavior in the dental office was a significant factor as to the amount of time that had past since the child's last dental visit, the child's ability to get care when needed and whether the child had a periodic dental provider. Income was significantly related to being able to get care when needed and having a periodic dental provider. No factors were significant as of to whether a child was currently scheduled. Travel times were highly correlated with convenience with people having to travel more than one hour stating that receiving treatment was not convenient at all.

Conclusion: Children with difficult behavior were statistically less likely to have a dentist for routine care, have longer intervals between treatment appointments and be less likely to receive care when needed. Pediatric dentists are treating the majority of these children. Twenty four percent of the children did not have a dentist for periodic oral health care. The most frequent reason for not being scheduled for a dental appointment was an inability to find a dentist with special skill or willingness to work with people having disabilities.

Introduction

Children with autism present a unique challenge for the dental community. Autism impacts the normal development of the brain in the area of social interaction and communication and encompasses a broad spectrum of disorders that may range from mild to severe. Children with autism, because of impaired language, lack of eye contact, lack of social interaction, repetitive behavior and a need for a rigid routine, present more of a challenge to the dentist than children with other handicapping conditions.[1] As communication is the key to behavior management in pediatric dentistry, the inability to reason with a patient having autism makes it difficult for the practitioner to provide comprehensive care.

The affects of oral disease can burden individuals throughout their lives. Nearly every American has experienced tooth decay and children are especially susceptible to oral disease.[2] National surveys report that around 7 percent of children have unmet needs and that children with no insurance are 2.5 times less likely to receive dental care and 3 times more likely to have unmet dental needs.[3] There are almost a million children under the age of 6 and 4.5 million children between 6 and 16 years old that fit the definition of being disabled[2]. It is estimated that 8.1 percent of children with special needs had unmet dental needs in 1994 and 1995.[4,5] Several studies reporting from the parent's perspective found that 13 to 75 percent of children with special needs had problems in obtaining dental

care.[2,6,7,8,9] Some of the barriers reported include difficulty with communication, excessive patient fear of unfamiliar people or settings, awkwardness of staff in dealing with a person with disabilities, financial disincentives, a need for sedation to complete dental care, having a severe disability, dentists not taking Medicaid and dentists lack of knowledge and training. These barriers have generally shown that dental health access of these individuals is poorer and their needs are greater than those without disabilities. One study found that 40% of caretakers experienced difficulty in locating a dentist willing to treat their residents, despite the fact that 75% of the residents were cooperative enough to have dental treatment performed in the traditional dental setting.[7]

A lack of access to dental care has a direct effect on these individuals overall health and quality of life. Chronic toothaches from decayed teeth, missing and loose teeth, chipped or fractured teeth, loss of supporting bone, dental abscesses, malocclusion and misaligned teeth are conditions frequently observed in this population. People who cannot communicate their discomfort can suffer from severe dental pain that may go undetected for long periods of time. These conditions may result in self-injurious or aggressive behavior.[10] Delay in treatment of these problems eventually leads to more serious problems requiring more aggressive treatment and accompanied by an increase in cost.

Children with autism live in a world where repetition and a routine schedule is a must, neither of which is associated with a trip to the dentist. Many of the events children are exposed to in the dental office may agitate the autistic child. For example, a normal child may cover his eyes or ears in response to bright light or the sound of the hand piece

while a child with autism might be combative.[11] Minimizing exposure to adverse stimuli for autistic children within a dental office is difficult.

The difficulty with managing a patient with autism has been reported in the literature. Kamen et al. has said that patients with autism are probably the most difficult for any dentist to treat. Repetitive body motions (ritualism), echolalia, hyperactivity and low frustration threshold are the challenges a dentist faces in treating these children.[1] Furthermore, the autistic patient is inherently unresponsive to demonstrations and will resist any effort to establish personal contact with the dental personnel.[12]

Inconsistencies with reactions to conscious sedation further complicate the problem. Autistic patients often have atypical response patterns to pharmacological management and standard doses and drugs are frequently ineffective.[12] In these cases, patients may need to undergo general anesthesia to have their treatment completed.

An understanding of utilization of dental visits and the barriers that are preventing access to dental services is important in identifying opportunities for improvement in the oral health of this population. Further, by determining the problems families face in obtaining dental care for children with autism, health care professionals can work to minimize the problems encountered. The purpose of this study was to analyze the utilization of dental services and to identify barriers from the parents' perspective that children with autism spectrum disorders face when accessing dental services in the state of Virginia.

Methods

A survey was developed in a previous study to look specifically at the barriers the autistic population faces with access to dental care.[16] The survey assessed families experiences with receiving dental care for their child with an autism spectrum disorder, their perception of how well their child's dental needs were met, and also addressed socioeconomic factors such as the parent/guardian's education and income level.

This survey was used as the means of data collection and was mailed to families in the state of Virginia that care for at least one child with the neuro-developmental disorder on the autism spectrum scale. A total of 200 surveys were mailed out. Included with the survey was a cover letter explaining the purpose of the study and a stamped, addressed return envelope. Non-respondents were mailed a postcard at two weeks and an additional cover letter, questionnaire and return envelope at four weeks, encouraging them to reply. A deadline was set at six weeks following the initial mailing.

The addresses for this mailing were obtained from The Autism Program of Virginia (TAPVA) database. Their mailing list contains the names of families/guardians of children with autism spectrum disorders. These individuals live throughout the State of Virginia.

Twenty survey questions were chosen for analysis because of their direct relationship with access issues and socioeconomic factors (Fig 1). These questions were also similar to those addressed in other surveys.[3,14-16] Univariate distributions were

obtained for each of these. Since not all respondents answered each question, the denominator used to calculate the proportions was the total number of non-missing values.

A set of five questions dealing with access issues was used which included: 1) does your child have a periodic health care provider, 2) time since last dental visit, 3) within the past year, was there a time when you needed dental care but was unable to get it, 4) is your child currently scheduled for a checkup within the next 12 months and 5) has your child ever been refused treatment. Other questions consistently found in the literature that were related to dental services were also included. These were questions inquiring about diagnosis, past behavior of child in dental office, health care coverage, and socioeconomic factors (age, income, education) that were chosen for comparison with the five questions analyzing access to care issues. Due to sample size and response distributions across categories some categorical levels were combined for analysis. These included age, income, education, behavior, ease of locating a dentist and time since last visit.

First, two-way contingency tables were inspected for relationships between socioeconomic factors and a child's ability to access care. Since these socioeconomic factors are not independent of one another, any factor in this analysis found to be significant at a p value of $p<.20$ was entered into a multiple logistic regression analysis to help eliminate dependencies. Factors found to have a p value of $p < .05$ in the multiple regression analysis were independently significant as to a child's ability to access care. Then, factors with $p> .05$ were removed. The final tables include only those socioeconomic characteristics found to be significant.

Results

From the 200 distributed surveys, 55 usable ones were returned. The overall sample size of the study was reduced from n=200 to n=188 due to twelve undeliverable surveys, resulting in an overall response rate of 29%. The subject's ages ranged from 3 to 20 years old with a mean of 9 and a standard deviation of 5. The majority of the children were white (78%), male (71%) and between the ages of 3-11 years of age (70%). Most of the families had an average income over $50,000 (59%). The education level of respondents was evenly distributed among those who had received only a high school diploma, those who had some college and those who had received an associate's degree (31% each) (Table 1).

The most commonly reported diagnosis was autism (60%) followed by Asperger's Syndrome (24%), Pervasive Developmental Disorder (PDD) (5%), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (7%), and 4% had a diagnosis other than those listed. No surveys for children with Childhood Disintegrative Disorder or Rett's Syndrome were returned (Table 1). No significant relationship was found between access to dental services and the child's diagnosis.

The majority of these patients behavior in the dental office was rated as "somewhat cooperative" to "cooperative" (67%) by the parents. Only 33% were described as extremely uncooperative and/or excessively fearful such that general anesthesia was

required for treatment (Table 1). Seventy five percent of the sample indicated no sedation was needed for checkups or cleanings, but 71% needed sedation for restorative treatment. General anesthesia was required for 7% to perform routine checkups and cleanings and 35% required general anesthesia for treatment.

Twenty four percent stated they did not have a dentist for periodic oral health care (Table 2). In the two-way contingency tables, education, income and behavior were the only factors significant at $p < 0.2$ (Table 3). Only behavior and income remained significant in the multiple regression analysis ($p < .05$) with extremely uncooperative behavior and an income between $20,000 and $49,000 being less likely to have a regular dentist (Table 4). Seventy percent of respondents' children had seen a dentist within the past year, 15% had not seen a dentist for greater than one year and 15% had never been (Table 2). In the two-way contingency table, age, education and behavior were the only factors significant at $p < 0.2$ (Table 5). When these factors were analyzed in the multiple regression analysis, only behavior remained significant ($p = .0125$) as to whether they were being seen on a regular basis, with the extremely uncooperative children being less likely to have been seen. As for being able to locate a dentist to treat their child, 48% reported it was at least "somewhat easy" and 15% said "very difficult" to "cannot locate one" (Table 2). Nine percent reported travel times of greater than one hour and 76% were less than 30 minutes away from their child's dental office (Table 2). Travel time and convenience were highly correlated.

Thirty-one percent of respondents' children were not currently scheduled for a checkup within the next 12 months (Table 2). The only two factors significant in the 2-

way contingency tables ($p < 0.2$), education and behavior, were insignificant in the multiple regression analysis (Table 6). Therefore, no socioeconomic factors were significant as to whether a child was currently scheduled for a check-up. Families were asked to indicate the reason why their child was not scheduled by checking all boxes that apply. Therefore, the percents given do not add up to 100%. The most frequent reason for not being scheduled was an inability to find a dentist with special skill or willingness to work with people having disabilities (46%). The other reasons given were, no dental services available in my area (11%), can not find a dentist who participates in Medicaid (11%), going under general anesthesia for exams and cleaning was too risky (11%) and child is too young (11%)(Table 2). Families who felt their child was "too young" to be scheduled, all had children over 3 years of age.

Nineteen percent of the families reported they were unable to receive dental care within the last year when needed. Having been refused treatment is a similar type of question, to which 25% reported that they had been. This question is also correlated with the question regarding reasons for not being scheduled. The most common reason stated for denial of services was "dentist not trained/comfortable treating patients with autism spectrum disorders." Other common responses included, "Medicaid waiver program not accepted, "dental office not properly equipped" and "currently not accepting new patients." Income, education, behavior and age were all significant in the 2-way contingency table, as to whether a child was able to receive care when needed (Table 7). Only behavior and income remained significant ($p<.05$) in the multiple regression analysis with extremely

uncooperative behavior and families in the $20,000 to $49,000 income bracket being less likely to receive care when needed (Table 8).

All of the respondents had some type of health care coverage. Twenty percent reported their insurance does not cover any services related to autism, 60% reported that their insurance covers some of these services and only 20% had insurance that covered all services related to autism (Table 1). Table 9 shows the insurance coverage distribution for the families surveyed. The majority (62%) relied on private insurance only. Thirteen percent of respondents relied only on Medicaid. Others had a combination of insurance carriers. The degree of health insurance coverage was not found to be statistically significant for obtaining dental care.

Discussion

Children with autism face many barriers to needed oral health care. The purpose of this study was to analyze the utilization of dental services and to identify barriers that children with autism spectrum disorders face when accessing dental services in the state of Virginia. Although the low response rate is a limitation of this study, 29% is considered to be in the normal range for surveys.[16] This study assumed that families having problems accessing services for their special needs child would be eager to respond to a survey that could ultimately help them access these services. The primary reason for the lower response was probably the length of the survey. Although it was stated in the cover letter that it would only take 10-15 minutes to complete, the appearance of the survey may have conveyed more of a required effort to the family.

The TAPVA list in itself may be biased towards a higher socioeconomic class of people since an individual must take the first step to be on this list by searching out the organization for information. It was not surprising to find that the majority of these children came from white families with advanced educations and higher than average incomes due to the dynamics of the list. People in this socioeconomic class tend to be more aware and were probably not as overwhelmed by the length of the survey. They are also more active in seeking treatment options and are motivated to do things that could benefit their child. Given the biasness of the list, it is believed that access to dental care for

this population is underestimated, as our results are a best-case scenario. Another limitation of this study is that the findings are based on subjective data collected from parents and/or guardians.

Children with difficult behavior were statistically less likely to have a dentist for periodic care, have longer gaps between treatment appointments and be less likely to receive care when needed. Although 68% of parents described their children as being at least "somewhat cooperative," 61% are being treated by pediatric dentists (Table 2). It was encouraging to see a general dentist was treating 35% of these "somewhat cooperative" patients, but more could be seen as 75% of the children required no sedation for check-ups or cleanings. Except for the occasional use of nitrous oxide/oxygen inhalation analgesia, the overwhelming majority of patients with autism can be treated in a conventional dental environment.

Frequency of visits to a health care provider has been used in national surveys as indicators of unmet dental health needs.[2] This study found that 30% of children with autism spectrum disorders had never seen a dentist or had not been within the past year (Table 2). As the Academy of Pediatric Dentistry recommends routine care at intervals no longer than one year, we feel that 30% closely represents the unmet dental needs of children with autism spectrum disorders in the state of Virginia. This is very close to the 27% of unmet needs found among special needs children in Alabama and significantly higher than the 6-7% reported by the 1993 National Health Insurance Survey (NHIS) for unmet dental needs of children in the general population.[16] Those that did not have a regular provider or had not been seen were younger children or those with uncooperative

behavior. The need to educate families about the importance of a dental examination at an earlier age is a key factor in controlling dental disease among these children. Establishing routine dental care early in life is essential to avoid dental disease and to combat existing disease before it escalates. Developing a referral program with the medical profession can also help promote oral health for children with autism spectrum disorders.

A lack of dentist training, as the most common reason why children were not currently scheduled for a dental appointment, indicates a lot of work still needs to be done among the dental community to increase skills and willingness of providers to care for these children. Many practitioners do not feel confident in treating children with special needs. This stems from a lack of opportunity in dental school to treat these types of patients. More than 50 percent of U.S. and Canadian dental schools offered fewer than five hours in didactic instructions, and 73 percent devoted less than 5 percent of clinical time to the dental care of children with disabilities.[17] Increasing the competence of dental students by providing clinical experiences in treating these patients, as well as providing continuing education courses addressing the treatment of special needs patients, are ways to increase our efforts to better serve this population.

Parents' perception of their ability to access dental care was analyzed through questions regarding their ability to locate a dentist, refusal of care and being able to receive care when needed. Other surveys, using similar questions, found 35-75% of parents had problems finding dentists willing to treat their child and 23% were unable to receive care when needed.[6,8,16,18] This study found that 15% were unable to find a provider or found it very difficult, 19% were unable to receive care when needed and 25% had been refused

treatment (Table 2). These problems could be overcome by better training of dentists, increasing awareness of parents about the need for early intervention and increasing the number of Medicaid providers.

One hundred percent of those surveyed had some kind of health care coverage. These insurance plans ranged from Medicaid to private insurance. Edelstein found more than 36% of children and adolescents have no dental insurance.[3] This study found that 20% did not have insurance that covered all services. Another major limitation of this study is that questions regarding insurance did not distinguish between types of services covered, e.g. dental vs. medical. Therefore it was assumed that services that were not covered included dentistry. It is interesting to note though, that insurance coverage was not a factor as to whether a child received care. Presence or absence of insurance coverage did not appear to influence the use of dental services. Contradictions on insurance as a barrier are reported in the literature. The majority of these studies do report that not having insurance is a barrier, with children having no insurance being 2.5 times less likely to receive dental care.[6,19-25] The reason that insurance may have been insignificant in this study could be that Medicaid, which covers dental services, often covers the lower socioeconomic people and/or the uninsured children's parents had high enough incomes to pay for dental services, making access less problematic.

Income was found to significantly predict whether a child had a dentist for periodic oral health care. Those in the income bracket of $20,000 to $49,000 were less likely to have a regular dentist (Table 4). People in this income bracket tend to be enrolled in insurance policies that are less comprehensive than Medicaid and may not have the money

to pay for dental services. One hundred percent of those that made less than $20,000 had a periodic oral health care provider (Table 3). This is most likely due to being enrolled in the Medicaid program where dental services are included.

When comparing results of different surveys, one must be aware of several limitations. The study of survey response error has revealed several cognitive variables that affect an individual's response to a survey.[22, 27] These include understanding the question, being able to share personal experiences in an objective way, and being honest by not withholding information or reporting what they think the interviewer wants to hear.

The type of survey instrument used may also add variation. In a telephone survey, the sequence usually does not allow the respondent to go back over questions. In addition, long pauses may make respondents feel pressured to respond quickly. Phone surveys also have the advantage of assessing non-verbal cues and interviewers can take steps to maintain respondent motivation. In a self-administered survey, there is time to review the questions before responding, but no motivation from a surveyor to complete the survey.

Even among surveys using the same method, slight variations can result in different interpretations of the question. Responses can vary depending on both the question and survey method. In spite of these limitations, we feel we can generalize these findings because surveyed groups had similar socioeconomic backgrounds and responded to similar questions that left little room for interpretation.

Conclusion

- Children with difficult behavior were statistically less likely to have a dentist for routine care, have longer intervals between treatment appointments and be less likely to receive care when needed.
- Income between $20,00-49,000 was significant for accessing care when needed and having a regular dental provider.
- Education and household income were not predictive of whether a child was currently scheduled for a dental examination.
- Short travel time and convenience were highly correlated with children receiving dental care.
- Seventy five percent of the sample indicated no sedation was needed for checkups or cleanings, but 71% needed sedation for restorative treatment.
- Pediatric dentists are treating the majority of these children.
- Twenty four percent of the children did not have a dentist for periodic oral health care.
- The most frequent reason for not being scheduled for a dental appointment was an inability to find a dentist with special skill or willingness to work with people having disabilities.

Table 1 Descriptive Characteristics of Socioeconomic and Behavioral Factors.

Socioeconomic Characteristics	N	Percent
Diagnosis	55	100
Autism	33	60
Asperger's Syndrome	13	24
PDD	3	5
PDD-NOS	4	7
Other	2	4
Insurance Coverage	54	100
Covers all services	11	20
Covers some services	32	60
Does not cover service	11	20
No health insurance	0	0
Age* (years)	55	100
3-5	19	35
6-11	19	35
12+	17	30
Sex	55	100
Male	39	71
Female	16	29
Race	55	100
White	43	78
Black	8	15
Asian	1	2
Hispanic	2	4
Other	1	2
Education	55	100
11th grade or less	2	4
H.S. diploma/GED	17	31
Some college	17	31
Associate degree	17	31
Bachelor Degree	2	4
Household Income	54	100
< $20,000	4	7
$20,000-49,999	18	33
$50,000+	32	59
History of behavior in dental office	49	100
Cooperative	20	41
Somewhat uncooperative	13	26
Extremely uncooperative	16	33

* Age was recorded in years and collapsed into these three groups

Table 2 Descriptive Characteristics of Access to Care and Utilization of Dental Services.

Access Characteristics	N	Percent
Has a Dentist for Periodic Care	55	100
Yes	42	76
No	13	24
Time Since Last Visit	55	100
Have not been	8	15
within 1 year	39	70
more than 1 year	8	15
Type of Provider	46	100
General dentist	16	35
Pediatric Dentist	28	61
Oral Surgeon	1	2
Don't Know	1	2
Travel Time	45	100
<30 minutes	34	76
30 minutes to 1 hour	7	16
1 to 2 hours	4	9
Convenience of Location	45	100
Convenient	36	80
Not convenient	9	20
Within past year, was child unable to get care when needed	54	100
Yes	10	19
No	44	81
Currently scheduled for check-up	55	100
Yes	38	69
No	17	31
Reasons why not scheduled	19*	
Cannot find a dentist to see special needs kids	9	46
No services available	2	11
No Medicaid participating dentist in area	2	11
Undergoing general anesthesia too risky	2	11
Child too young	2	11
Other	2	11
How difficult is it for you to locate a dentist	52	100
Very difficult or cannot locate one	8	15
Somewhat difficult	19	37
Somewhat easy to easy	25	48
Ever Refused Treatment	52	100
Yes	13	25
No	39	75

*Those surveyed could check as many as applied.

Table 3 Comparison of Dental Provider with Socioeconomic and Behavioral Factors

		Does your child have a dentist for periodic oral health care?		
Socioeconomic Characteristics	**N**	**%Yes**	**%No**	**p-value**
Diagnosis				0.5684
Autism	33	73	27	
Asperger's Syndrome	13	77	23	
PDD	3	100	0	
PDD-NOS	4	75	25	
Other	2	100	0	
Insurance Coverage				
Covers all services	11	73	27	0.8744
Covers some services	32	78	22	
Does not cover service	11	82	18	
No health insurance	0			
Age (years)				0.3558
3-5	19	68	32	
6-11	19	74	26	
12+	17	88	12	
Education				0.0018*
11th grade or less	2	100	0	
H.S. diploma/GED	17	41	59	
Some college	17	88	12	
Associate degree	17	94	6	
Bachelor Degree	2	100	0	
Household Income				0.0368*
< $20,000	4	100	0	
$20,000-49,999	18	56	44	
$50,000+	32	84	16	
History of behavior in dental office				0.0047*
Cooperative	20	90	10	
Somewhat uncooperative	13	100	0	
Extremely uncooperative	16	56	44	

*Significant at $p<0.2$ and therefore re-analyzed in the multiple regression analysis.

Table 4 Significant Socioeconomic and Behavioral Factors Associated with Dental Provider Status

		Does your child have a dentist for periodic oral health care?		
History of past behaviors*	**Household income***	**Yes**	**No**	**%Yes**
Cooperative	$20,000-49,999	6	2	75%
Cooperative	$50,000 +	11	0	100%
Cooperative	Not Reported	1	0	100%
Somewhat uncooperative	< $20,000	3	0	100%
Somewhat uncooperative	$20,000-49,999	3	0	100%
Somewhat uncooperative	$50,000 +	7	0	100%
Extremely uncooperative	< $20,000	1	0	100%
Extremely uncooperative	$20,000-49,999	1	4	20%
Extremely uncooperative	$50,000 +	7	3	70%
Not Reported	$20,000-49,999	0	2	0%
Not Reported	$50,000 +	2	2	50%

* History (p-value = 0.0012), and income (p-value = 0.0190) significantly predicts having a dental provider by logistic regression.

Table 5 Comparison of Time Since Last Treatment with Socioeconomic Factors

		The last time your child received dental care			
Socioeconomic Characteristics	**N**	**% Have not been**	**% within 1 yr.**	**% > 1 yr.**	**p-value**
Diagnosis					0.8309
Autism	33	18	64	18	
Asperger's Syndrome	13	8	77	15	
PDD	3	0	100	0	
PDD-NOS	4	25	75	0	
Other	2	0	100	0	
Insurance Coverage					0.4260
Covers all services	11	0	73	27	
Covers some services	32	16	75	9	
Does not cover service	11	18	64	18	
No health insurance	0				
Age (years)					0.0976*
3-5	19	32	63	5	
6-11	19	5	74	21	
12+	17	6	76	18	
Education					0.0817*
11th grade or less	2	0	50	50	
H.S. diploma/GED	17	29	41	29	
Some college	17	12	82	6	
Associate degree	17	6	88	6	
Bachelor Degree	2	0	100	0	
Household Income					0.4186
< $20,000	4	0	100	0	
$20,000-49,999	18	22	56	22	
$50,000+	32	13	75	13	
History of behavior in dental office					0.0292*
Cooperative	20	5	85	10	
Somewhat uncooperative	13	0	100	0	
Extremely uncooperative	16	13	56	31	

* Significant at $p<0.2$ and therefore re-analyzed in the multiple regression analysis.

Table 6 Comparison of Scheduled Dental Checkup with Socioeconomic Factors

		Currently schedule for a checkup within 12 mo.		
Socioeconomic Characteristics	**N**	**%Yes**	**%No**	**p-value**
Diagnosis				0.4405
Autism	33	64	36	
Asperger's Syndrome	13	77	23	
PDD	3	100	0	
PDD-NOS	4	50	50	
Other	2	100	0	
Insurance Coverage				0.8593
Covers all services	11	73	27	
Covers some services	32	72	28	
Does not cover service	11	64	36	
No health insurance	0			
Age (years)				0.2706
3-5	19	58	42	
6-11	19	68	32	
12+	17	82	18	
Education				*0.1394
11th grade or less	2	100	0	
H.S. diploma/GED	17	47	53	
Some college	17	76	24	
Associate degree	17	82	18	
Bachelor Degree	2	50	50	
Household Income				*0.1767
< $20,000	4	100	0	
$20,000-49,999	18	61	39	
$50,000+	32	69	31	
History of behavior in dental office				0.2291
Cooperative	20	85	15	
Somewhat uncooperative	13	85	15	
Extremely uncooperative	16	63	38	

*Factors significant at $p < .2$ were insignificant in multiple regression analysis.

Table 7 Comparison of Inability to Receive Care When Needed with Socioeconomic Factors

		Within the last year, was there a time when your child needed dental care but was unable to get it?		
Socioeconomic Characteristics	**N**	**%Yes**	**%No**	**p-value**
Diagnosis				0.7130
Autism	32	22	78	
Asperger's Syndrome	13	15	85	
PDD	3	33	67	
PDD-NOS	4	0	100	
Other	2	0	100	
Insurance Coverage				0.9810
Covers all services	11	18	82	
Covers some services	31	16	84	
Does not cover service	11	18	82	
No health insurance	0			
Age (years)				*0.0229
3-5	19	11	89	
6-11	18	39	61	
12+	17	6	94	
Education				*0.1625
11th grade or less	2	0	100	
H.S. diploma/GED	16	38	63	
Some college	17	18	82	
Associate degree	17	6	94	
Bachelor Degree	2	0	100	
Household Income				*0.0593
< $20,000	4	50	50	
$20,000-49,999	17	29	71	
$50,000+	32	9	91	
History of behavior in dental office				*0.006
Cooperative	20	5	95	
Somewhat uncooperative	13	8	92	
Extremely uncooperative	16	44	56	

*Only two factors significant at $p < .2$ were significant in multiple regression analysis (see Table 8)

Table 8 Significant Socioeconomic and Behavioral Factors Associated with Ability to Receive Care when Needed

		Within the last year, was there a time when your child needed dental care but was unable to get it?		
History of past behaviors*	**Household income***	**Yes**	**No**	**%Yes**
Cooperative	Not Reported	0	1	0%
Cooperative	$20,000-49,999	0	8	0%
Cooperative	$50,000 +	1	10	9%
Somewhat uncooperative	< $20,000	1	2	33%
Somewhat uncooperative	$20,000-49,999	0	3	0%
Somewhat uncooperative	$50,000 +	0	7	0%
Extremely uncooperative	< $20,000	1	0	100%
Extremely uncooperative	$20,000-49,999	4	1	80%
Extremely uncooperative	$50,000 +	2	8	20%
Not Reported	$20,000-49,999	1	0	100%
Not Reported	$50,000 +	0	4	0%

* History (p-value = 0.0014), and income (p-value = 0.0248) significantly predicts ability to receive care when needed by logistic regression.

Table 9 Insurance Distributions of Respondents

Insurance Type	N	%
Private Health Insurance	34	62
Health Managed Organization (HMO)	3	5
Health Managed Organization and Private Health Insurance	2	4
Medicaid	7	13
Medicaid + Private Health Insurance	5	9
Does not have Insurance	0	0
Other	4	7

Figure 1: Original Survey with Analyzed Question Numbers Highlighted.

Children with Autism Spectrum Disorders

1. This survey concerns children with **autism spectrum disorders.** Do you have one or more children with an **autism spectrum disorder?** By this we mean a documented medical diagnosis of Pervasive Developmental Disorders (PDD), Autism, Asperger's Syndrome, Pervasive Developmental Disorders Not-Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder, or Rett's Disorder.

- ❒ Yes, one child only with autism spectrum disorder
- ❒ Yes, more than one child with autism spectrum disorder (**please answer the survey thinking about the child with autism spectrum disorder who visited the dentist MOST RECENTLY. If no children with autism spectrum disorder have visited the dentist, please answer the survey thinking about the oldest child with autism spectrum disorder.**)
- ❒ No, no children with autism spectrum disorder (**please stop here and return the survey**)
- ❒ Don't know/Not sure (**please stop here and return the survey**)

2. How old was your child when he/she was first diagnosed with an autism spectrum disorder?
_____ Years

3. What diagnosis best describes your child?

- ❒ Autism
- ❒ Asperger's Syndrome
- ❒ Childhood Disintegrative Disorder
- ❒ Pervasive Developmental Disorder (PDD)
- ❒ Pervasive Developmental Disorder-Not otherwise Specified (PDD-NOS)
- ❒ Rett's Disorder/Rett's Syndrome
- ❒ Other (**please list**): _____

4. Did you receive any information about medical services (including dental services) or community resources at the time when your child was initially diagnosed with an autism spectrum disorder?

- ❒ Yes
- ❒ No

5. Does your child have any of the following medical conditions?

- ❒ Heart problems (**please specify**): _____
- ❒ Liver problems (**please specify**): _____
- ❒ Kidney problems (**please specify**): _____
- ❒ Lung problems (**please specify**): _____
- ❒ Other (**please list**): _____

6. What types of medications related to his or her autism spectrum disorder does your child take?

- ❒ Decongestants
- ❒ Antihistamines
- ❒ Anticonvulsants
- ❒ Other (**please list**): _____

7. Does your child (**please check all that apply**):

- ❒ Have dry mouth
- ❒ Respond to verbal stimuli
- ❒ Follow verbal commands
- ❒ Become difficult to manage when there is a change or break in routine
- ❒ Use a wheel chair
- ❒ Have or do other things continually out of habit (please list):_____
- ❒ "Pocket" (that is, store) food in his/her mouth for long periods of time?

8. How often do your child's teeth get brushed? (**please check one**)

- ❒ More than once a day
- ❒ Once a day
- ❒ 2-6 times a week
- ❒ Once a week or less frequently
- ❒ Don't know

9. How often does your child require help to brush his/her teeth? (**please check one**)

- ❒ Always
- ❒ Most of the time
- ❒ Some of the time
- ❒ Rarely
- ❒ Never

10. How difficult is it for you or your child's primary caregiver to brush your child's teeth? (**please check one**)

- ❒ Unable to brush child's teeth
- ❒ Very difficult
- ❒ Somewhat difficult
- ❒ Somewhat easy
- ❒ Easy

11. Does your child have a dentist for emergency dental care? (injury, facial swelling, toothaches, etc.)

- ❒ Yes (**continue with question 12**)
- ❒ No (**skip to question 13**)

12. Where does your child receive their emergency dental care? (**please check all that apply**)

- ❒ Dental office
- ❒ Hospital emergency room
- ❒ Other (**please list**): _____

13. Does your child have a dentist for periodic oral health care (that is, examinations, preventive procedures, and routine treatment)?

- ❒ Yes
- ❒ No

14. How difficult is it for you to locate a dentist who will treat your child? (**please check one**)

- ❒ Cannot locate one
- ❒ Very difficult
- ❒ Somewhat difficult
- ❒ Somewhat easy
- ❒ Easy

15. How much time passes from the day you schedule your child's appointment to the day your child is seen by the dentist? (**please check one**)

- ❒ 1 week or less
- ❒ 2-4 weeks
- ❒ 1-3 months
- ❒ More than 3 months

16. Please indicate the last time your child received dental care from a dentist or dental hygienist. (**please check one**)

- ❒ Has not received dental care (**skip to question 26**)
- ❒ Within the last 6 months
- ❒ 6+ months to 1 year ago
- ❒ 1+ to 2 years ago
- ❒ 2+ to 4 years ago
- ❒ Over 4+ years ago
- ❒ Don't know

17. Do you know what type of dental care provider your child saw? (**please check one**)

- ❒ General dentist
- ❒ Pediatric dentist
- ❒ Oral surgeon
- ❒ Dental hygienist only
- ❒ Don't know
- ❒ Other (**please list**): _____

18. Approximately how much time did your child's last dental cleaning and checkup take (not counting time in the waiting room)?

- ❒ 1-30 minutes
- ❒ 31-60 minutes
- ❒ 61-90 minutes
- ❒ More than 90 minutes

19. How much time did it take you to travel to your child's most recent dental visit? (**please check one**)

- ❒ Less than 30 minutes
- ❒ Between 30 minutes to 1 hour
- ❒ Between 1 and 2 hours
- ❒ More than 2 hours

20. Considering the distance or time you traveled to receive dental care, how would you rate the convenience of that location? (**please check one**)

- ❒ Very convenient
- ❒ Somewhat convenient
- ❒ Not too convenient
- ❒ Not at all convenient

21. In your opinion as a parent or guardian what mental or physical conditions does your child have that pose the greatest barrier to receiving dental care? (**please specify**):

_____

_____

22. Has the dentist or dental hygienist ever had to use restraints (e.g. holding arms, hands, mouth prop, and or full body restraint) in order to do your child's dental work?

❒ No
❒ Yes (**please describe what the restraints were**):

_____
_____

23. In what settings are dental procedures for your child usually performed? (**please check all that apply**)

A. Cleanings and Checkups:

❒ Dental office
❒ Hospital
❒ Other

B. Treatments (Fillings, Crowns, Extractions, Dentures, etc.):

❒ Dental office
❒ Hospital
❒ Other

24. In the past, what type of sedation or anesthesia has your child received for dental work performed within a traditional office setting? (**please check all that apply**)

A. Cleaning and Checkups:

❒ No sedation
❒ Sedative taken at home prior to the dental appt. (example: Valium®)
❒ Nitrous oxide (laughing gas)
❒ Oral medication taken at the dental office to make child drowsy
❒ General anesthesia (putting child to sleep)

B. Treatments (Fillings, Crowns, Extractions, Dentures, etc.):

❒ No sedation
❒ Sedative taken at home prior to the appt. (example: Valium®)
❒ Nitrous oxide (laughing gas)
❒ Oral medication taken at the dental office to make child drowsy
❒ General anesthesia (Putting child to sleep)

25. Please select the best description of your child's past behaviors as a patient in the dental office:

❒ Your child 1) is cooperative at dental office, 2) is not excessively fearful of dentist or assistant and 3) requires only local anesthetic, sometimes enhanced by a sedative taken prior to the appointment.

❒ Your child 1) is somewhat uncooperative in dental settings 2) is fearful of dentist and assistants 3) may require nitrous oxide during treatment or 4) may require some form of oral medication to make child sleepy.

❒ Your child 1) is extremely uncooperative in dental settings 2) is excessively fearful of dentists and assistants 3) requires general anesthesia (having child put to sleep) due to being extremely uncooperative.

26. Within the last year, was there a time when your child needed dental care but was unable to get it?

❒ Yes
❒ No
❒ Don't know

27. Is your child currently scheduled for a dental checkup sometime within the next 12 months?
- ❒ Yes (**skip to question 29**)
- ❒ No (**continue with question 28**)

28. Please indicate the reasons why your child is not currently scheduled for a dental checkup sometime within the next 12 months. (**check all that apply**)
- ❒ I cannot find a dentist with special skill or willingness to work with people having disabilities (i.e., autism spectrum disorders)
- ❒ There are no dental services available in my area of the state
- ❒ My child's health insurance does not cover dental services
- ❒ I cannot find a dentist who participates in the Medicaid Waiver Program
- ❒ I cannot get transportation to the dental office
- ❒ Other reason (please specify): _____
  _____

29. Has a dentist or dental office ever refused to treat your child?
- ❒ Yes (**continue with question 30**)
- ❒ No (**skip to questions 33**)

30. When a dentist refuses to treat your child do you know why?
- ❒ Yes (**continue with question 31**)
- ❒ No (**skip to question 33**

31. If your child was refused dental treatment please indicate the reason stated by the dental office. (**Check all that apply**)
- ❒ Currently not accepting new patients
- ❒ Medicaid Waiver Program not accepted
- ❒ Dentist not trained/comfortable treating patients with autism spectrum disorders
- ❒ Dental office not properly equipped to care for patients with autism spectrum disorders

32. In your opinion, were other factors involved that were not stated by the dental office when your child was refused dental care?
- ❒ No
- ❒ Yes (**please explain**):

_____
_____

33. Does your child have any kind of health care coverage including but not limited to: (**check all that apply**)
- ❒ Private health insurance (**continue with question 34**)
- ❒ Prepaid plans such as HMO's (Health Managed Organizations)
- ❒ Government plans such as the Medicaid Waiver Program
- ❒ My child has does not have any health care coverage (**skip to question 35**)
- ❒ Other (**please list**): _____

34. Which of the following statements best describes the health care coverage for your child with an autism spectrum disorder? (**please check one**)
- ❒ My health care coverage covers all services related to autism spectrum disorders
- ❒ My health care coverage covers some services related to autism spectrum disorders
- ❒ My health care coverage does not cover any services related to autism spectrum disorders
- ❒ My child does not have any health care coverage

35. Gender of Child:
- ❒ Male
- ❒ Female

36. Age of Child: ____ years

37. Is your child Spanish/Hispanic/Latino? (**please check one**)
- ❒ No, not Spanish/Hispanic/Latino
- ❒ Yes, Mexican, Mexican American, Chicano
- ❒ Yes, Puerto Rican
- ❒ Yes, Cuban
- ❒ Yes, other Spanish/Hispanic/Latino (**specify**): _____

38. What is your child's race? (**check all that apply**)
- ❒ White
- ❒ African American
- ❒ American Indian or Alaska Native
- ❒ Asian
- ❒ Other _____

39. Your Age: ____ years

40. What is your relationship to the child in question? (**please check one**)
- ❒ Parent
- ❒ Stepparent
- ❒ Legal guardian
- ❒ Other (please list): _____

41. Do you: (**please check one**)
- ❒ Own your home/apartment
- ❒ Rent home/apartment

42. How long have you lived at your current address? (**please check one**)
- ❒ Less than 6 months
- ❒ 6-12 months
- ❒ 1-2 years
- ❒ More than 2 years
- ❒ Don't know/not sure
- ❒ Refused

43. In what county or independent city do you live?

_____

44. Including yourself how many people live in your household: _____

45. Are you: (**please check one**)
- ❒ Married
- ❒ Widowed
- ❒ Divorced
- ❒ Never married
- ❒ Other

46. What is your current employment status? (**please check one**)

- ❒ Employed full-time
- ❒ Employed part-time
- ❒ Unemployed looking for work
- ❒ Retired
- ❒ Homemaker
- ❒ Student
- ❒ Other (**please list**): _____

47. If married, what is the current employment status of your spouse? (**please check one**)

- ❒ Employed full-time
- ❒ Employed part-time
- ❒ Unemployed looking for work
- ❒ Retired
- ❒ Homemaker
- ❒ Student
- ❒ Other (**please list**): _____

48. Including all sources of income, please indicate your approximate household income in 2002, before taxes:

- ❒ Less than $10,000
- ❒ $10,000-$19,999
- ❒ $20,000-$34,999
- ❒ $35,000-$49,999
- ❒ $50,000-$74,999
- ❒ $75,000-$99,999
- ❒ $100,000 or more

49. What is the highest level of school you completed? (**please check one**)

- ❒ 11th grade or less
- ❒ High school, diploma or G.E.D.
- ❒ Some college
- ❒ Associate degree
- ❒ Bachelor degree
- ❒ Postgraduate degree

50. Please use the space below to tell us anything else about these issues, or about the survey itself. Thanks again for taking time to share your opinions.

_____

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Literature Cited

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Vita

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