# Feeding problems and GI dysfunction in children with asperger syndrome or pervasive developmental disorder not otherwise specified; comparison with their siblings

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## ABSTRACT

**Objective: There are few previously published studies** of feeding problems and/or gastrointestinal dysfunction among children with Asperger syndrome (AS) or Pervasive Developmental Disorder (PDD-NOS), compared to sibling controls. Study Design: On-line parent autism groups 90% from North America. Statistical analysis: Chi square and binomial logistic regression statistical analysis Results: Completed surveys were received for 64 children with AS, 44 with PDD-NOS, total = 108), and 82 normal sibling matches. Children with high-functioning autism had higher likelihood of frequent (>50% of the time) problematic feeding behaviors and gastrointestinal dysfunction, such as unusual food preferences (OR 23.9, 95% CI 7.3 - 78.7), insistence on unusual food presentation (OR 5.8, 95% CI 1.8 - 18.4), and poor mealtime social behavior (OR 16.1, 95% CI 4.1 -64.1). These children also had higher odds of frequent constipation (OR 8.3, 95% CI 2.2 - 31.9) and fecal incontinence (OR 5.4, 95% CI 1.1 - 27.3). Nine children in AS/PDD-NOS group (4%) were believed by parent to have celiac disease (3% or 1% had intestinal biopsy), compared to 2 in control group. Conclusion: 57% of the AS/PDD-NOS group had frequent unusual food preferences vs. 5% of controls. Fortyeight percent of children with AS/PDD-NOS had frequent dislikes of new foods, compared to 6% of controls. For symptoms of specific gastrointestinal dysfunction, children with AS/PDD-NOS had higher prevalence of frequent constipation (30% vs. 4%) and fecal incontinence (22% vs. 2%).

**Keywords:** Asperger Syndrome; PDD-NOS, Feeding Behaviors; Gastrointestinal Dysfunction; Food Preferences

## **1. INTRODUCTION**

An estimated 1 in 110 children in the US and Canada are estimated to have a diagnosis of Autism Spectrum disorder and these rates have been increasing in the past decade [1]. Autism spectrum disorder (ASD), is a heterogeneous group of neuro-developmental disorders that the Diagnostic and Statistical Manual IV-R currently subdivides into three subgroups: Asperger syndrome, pervasive developmental disorder-not otherwise specified (PDD-NOS) which is the most common and has the least precise diagnostic criteria [2], and classical autism [3]. Children with PDD-NOS almost universally have impairments in social reciprocity and communication, without significant repetitive and stereotyped behaviors [4]. Compared to classic autism, they have comparably severe but more circumscribed social communication difficulties with fewer non-social features such as sensory integration or feeding problems. The current draft guidelines of the upcoming DSM-V will mandate repetitive and stereotyped behaviors in addition to major defects in language and communication and socialization [4].

Previous publications have documented increased rates of feeding problems and gastrointestinal dysfunction among children with ASD. Although opinions differ, a majority of published studies on the subject of childhood autism and gastrointestinal problems report higher rates of feeding problems in children with ASD compared to controls [5-13]. The Brief Autism Mealtime Behavior Inventory (BAMBI) has been developed to evaluate the mealtime behavior of children with autism [14]. The BAMBI demonstrated good internal consistency, high test-re-test reliability.

A recent study comparing 48 children (3 to 12 years old) with ASD, to their matched siblings found that the ASD group had a mean of 13 eating problems, with lack of food variety predomination while the sibling group had a mean of 5 eating problems [11]. Feeding problems



included inflexible food preferences (based on food texture, color, smell, presentation, limited variety diets, and specific utensil requirements), oral-motor dyspraxia and disruptive mealtime behaviors, among others. In a survey of 138 children with autism and 298 typically developing children, Schreck and colleagues (2005), found that children with autism had higher rates of refusing most foods, requiring specific utensils, requiring particular food presentation, accepting only pureed or low textured foods, and eating a narrow variety of foods [15]. Smith et al also found that children with ASD had a limited repertoire of foods (35% vs. 3%) [8]. Emond et al. (2010) found that caregivers of autistic children reported significantly more frequently feeding slow during early infancy, parent having difficulties feeding the child, and the child being a picky eater [16].

In 2011, investigators from the University of California reported that 249 children on the autism spectrum had significantly more GI problems (42%) than 163 siblings (12%). This study was registry-based and the investigators conducted in-home structured medical history interviews by parent recall. Those children with classic autism had increased odds of having GI problems compared to less severely affected children with ASD [12].

The most common symptoms of GI dysfunction include abdominal pain, dysphagia, gastrointestinal reflux (GER), constipation, withholding stool, and fecal incontinence [15]. Constipation rates among the children with autism was higher than control groups in the studies of Melmed [17], Taylor [18], Afzal [19], Molloy [7], and Smith [8].

In contradistinction, analysis of a database of 211,480 children from the United Kingdom found no difference in gastrointestinal complaints in 96 children diagnosed with ASD compared with 449 nested controls [20]. Investigators from the Mayo Clinic also found no significant associations between autism case status and overall incidence of GI dysfunction [21]. An Australian study concluded that children with early gastrointestinal problems were no more likely to be represented in the upper quartile of scores on the Autism Spectrum Quotient (AQ) scales [4].

The purpose of this study was to compare the prevalence of feeding difficulties and gastrointestinal dysfunction in children with Asperger syndrome and Pervasive Developmental Disorder (so-called high-functioning autism) and their typically developing siblings. Our intention was to use sibling controls in order to control for the influence of social environment.

#### 2. STUDY DESIGN AND PATIENT POPULATION

This was a cross-sectional online survey conducted from

February 2009 through April 2009. The lengthy survey instrument included 41 questions pertaining to demographics, family income, developmental milestones, feeding behaviors and odd mannerisms, food preferences, and GI dysfunction at the time when the child was between ages 3 and 12 (see appendix). The survey contained two almost identical parts, one for the child with AS or PDD-NOS and one for the typically-developing sibling. Both parts contained the same 41 questions with the exception of the question pertaining to ASD diagnosis (only available in ASD part). The survey was securely posted online at a commercial survey website http://www.formsite.com (Vroman systems Inc, Chicago, IL). At no point was the survey tool sold and no profits were generated from using the survey tool. The authors bore all the costs associated with publishing the survey online.

The link to the survey was e-mailed repeatedly to national, regional, state, and large city autism organizations and support groups. Parents were asked to complete the survey if they had a child with AS or PDD-NOS. If a parent had several children with ASD, he/she was asked to complete the survey separately for each ASD child. The survey was confidential and anonymous. The survey link contained an introductory statement about the purpose of the survey, voluntary participation, risks and benefits, and contacts of investigators and IRB officer.

The drafts of the survey were pre-tested on 10 parents of ASD children from a pediatric practice in Vienna, VA, and reviewed by local specialists in developmental/behavioral pediatrics, and pediatric gastroenterology. The survey protocol was approved without full formal review by Inova Fairfax Hospital Institutional Review Board.

#### 2.1. Definitions Used for This Study

Children were defined as having Asperger syndrome or PDD-NOS if the parents indicated so in the survey and, if the diagnosis was made by a primary care or pediatric sub-specialist physician or psychologist.

Definitions used in this study: We categorized the frequencies of feeding behaviors and gastrointestinal problems into "Never", "Rarely" (less than 10% of the time), "Sometimes" (10% - 50% of the time), and "Often" (more than 50% of the time).

"Diarrhea" was defined as passing at least three watery unformed stools in a day. "Constipation" was defined as hard or painful stools passed less than three times per week.

"Pica" was defined as the ingestion of unusual nonfood items such as dirt or string.

#### 2.2. Statistical Methods

Data was analyzed using SPSS version 18 (SPSS Inc.

Chicago, Illinois). Descriptive statistics (means and standard deviations) were used for continuous variables, and proportions were used for categorical variables. Fischer's exact test was used to compare dichotomous variables pertaining to feeding and gastrointestinal dysfunction between the groups. To control for influences of variables pertaining to age, gender, degree of developmental impairment, medical problems, country, food allergies, and dietary restrictions, binomial logistical regression models were created with these variables being included as independent variables, along with the autistic spectrum disorder variable (case vs. control). The variables pertaining to feeding and gastrointestinal dysfunction were included one by one in the regression model as a dependent variable.

# **3. RESULTS**

Surveys were completed for 64 children with Asperger Syndrome, 44 children with PDD-NOS (combined total = 108), and 82 of their typically-developing siblings. All participants were between the ages of 3 and 12 years. Males comprised 88% of the combined (AS/PDD-NOS) group and 50% of the control group (p < 0.001). Mean ages at the time of the survey were 7.9 years and 7.7 years in the ASD and control groups, respectively (p = 0.54, NS) (**Table 1**).

U.S. respondents comprised 85% of the ASPDD-NOS group and 78% of the control group (p = 0.25, NS). The highest numbers of U.S. respondents came from Virginia, Kansas, Texas, Indiana, and Missouri. Fifteen percent of completed responses came from Canada. A bare majority (52%) of the parent responders reported that their household income in 2008 exceeded \$75,000 per year (p = 0.84, NS). Approximately 5% of the control group was enrolled in Medicaid.

Cross-tabulations of children with Asperger syndrome and PDD-NOS showed that the two groups were, in general, similar in terms of most developmental mile-

Table	1.	Study	partici	pants.
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stones, food preferences and gastrointestinal dysfunction (chi square p values >0.05) (**Tables 2** and **3**). There were some specific developmental milestone differences between children with AS and those with PDD-NOS. The mean age at the time of diagnosis was 4-years for children with PDD-NOS versus 6.2 years for children with AS (independent samples t-test, p value < 0.001). Sixtyseven percent of PDD-NOS group versus 86% of children in the AS group were toilet trained by age of 4 (Chi square P value = 0.029). Acquisition of language by the age of 4 years was achieved by 55% of PDD-NOS group and by 88% of Asperger group (Chi-square P value < 0.001) (**Table 2**).

Because of the small number of differences for feeding problems or GI dysfunction, children with AS or PDD-NOS were combined into a single combined study group for subsequent analysis. Their typically-developing siblings were also combined into a single control group.

There were major differences between children with the combined AS/PDD-NOS and sibling controls in reportedly having any major developmental problem (AS/ PDD-NOS = 200 [96%] compared to 9 [6%] in control group, p < 0.000, OR = 337.8, CI = 114 - 1000.8), disortions or paucity of social play (AS/PDD-NOS = 103 vs controls = 2, p < 0.000, OR = 42.9, CI = 5.3 - 349.9), odd routines (AS/PDD-NOS = 139 vs control group = 3, p < 0.000, OR = 107.4, CI = 31.3 - 369.1), never spoke by age 4 years (AS/PDD-NOS = 40 vs controls = 1, p < 0.000, OR = 42.9, CI = 5.3 - 349.9) (**Table 3**).

The combined AS/PDD-NOS group differed signifycantly from the control group for frequent disruptive feeding problems. These included obsessional food preferences (*i.e.* insistence on: a. specific food colors, shapes, or textures, insistence on eating food with specific utensils/dishes, fear of new foods, and disruptive family mealtime behavior, (**Table 4**). Unusual food preference (frequency > 50% of time) was present for 127

	Control AS/PDD Combined group		Significant		
-	n = 82	%	n = 108	%	
Age	7.7		7.9		p = 0.54
St dev	2.8		2.7		
Male gender	41	50%	95	88%	p < 0.001
Live in USA	64	78%	92	85%	p = 0.25
Family income > \$75000/year	44	54%	55	51%	p = 0.84
Developmental Milestones Spoke by age 4	79	96%	80	74%	p < 0.001
Spoon trained by age 3	79	96%	83	77%	p < 0.001
Toilet trained by age 4	77	94%	83	77%	p < 0.001

GI symptoms	Asperger ( $n = 134$ )	PDD-NOS $(n = 71)$	Combined Asperger and PDD-NOS (n = 6)	Controls (n = 160)	Chi-Square P value
vomiting	12	2	2	5	p = 0.002
%	9.0%	2.8%	33.3%	3.1%	
diarrhea	10	12	2	4	< 0.001
%	7.5%	16.9%	33.3%	2.5%	
constipation	35	25	2	9	< 0.001
%	26.1%	35.2%	33.3%	5.6%	
soiling	27	21	5	7	< 0.001
%	20.1%	29.6%	83.3%	4.4%	
difficulty swallowing	6	11	2	4	< 0.001
%	4.5%	15.5%	33.3%	2.5%	
reflux	17	10	3	11	p = 0.004
%	12.7%	14.1%	50.0%	6.9%	
abdominal pain	11	5	2	6	p = 0.02
%	8.2%	7.0%	33.3%	3.8%	
failure to thrive	31	17	3	10	< 0.001
%	23.3%	25.0%	50.0%	6.4%	
any diet restriction	30	19	3	12	< 0.001
	22.4%	26.8%	50.0%	7.5%	
any food allergy	30	18	4	21	< 0.002
	22.4%	25.4%	66.7%	13.1%	

Table 2. Occurrence of select behaviors and GI symptoms that were frequent.

Table 3. Deviation from normal developmental milestones.

	AS/PDD-NOS		Contr	Controls		Logistic regression odds	
	n = 211	%	n = 160	%	exact test	ratio (95% CI)	
No Social Play	103	49%	2	1%	0.000	53.9 (12.8 - 227.2)	
Odd Mannerisms	174	82%	4	3%	0.000	159.4 (52.5 - 483.9)	
Odd Routines	139	66%	3	2%	0.000	107.4 (31.3 - 369.1)	
Any Major Developmental Problem	200	95%	9	6%	0.000	337.8 (114 - 1000.8)	
Mental Disability	6	3%	2	1%	0.474	1.3 (0.2 - 8.7)	

or 60% of the AS/PDD-NOS group vs. 9 or 6% of the control group (p < 0.001, OR = 38.4, CI = 15.4 - 95.8) (**Table 4**). Disruptive family mealtime behavior was noted for 74 or 35% of the AS/PDD-NOS group vs. 7 or

4% or the control group (p < 0.001, OR = 9.9, CI = 4 - 24.7).

The combined AS/PDD-NOS group differed significantly from the control group by the prevalence of se-

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Table 4. Abnormal Feeding behaviors, frequency >50% of the time.

Frequent (>50%) occurrence of select behaviors and gastrointestinal symptoms	Asperger $(n = 134)$	$\begin{array}{c} \text{PDD-NOS} \\ (n = 71) \end{array}$	Combined Asperger and PDD-NOS (n = 6)	Controls (n = 160)	Chi-Square P value
unusual food preferences	76	47	4	6	< 0.001
%	56.7%	66.2%	66.7%	3.8%	
insistence on using utensils	32	18	2	9	< 0.001
%	23.9%	25.4%	33.3%	5.6%	
dislike of new foods	62	42	5	9	< 0.001
%	46.3%	59.2%	83.3%	5.6%	
fear of new foods	73	50	3	20	< 0.001
%	54.5%	70.4%	50.0%	12.5%	
eating nonfood items (Pica)	12	9	2	2	< 0.001
%	9.0%	12.7%	33.3%	1.3%	
Disruptive family mealtime	41	29	4	7	< 0.001
behavior	30.6%	40.8%	66.7%	4.4%	
Disruptive school mealtime behavior	14	12	3	1	< 0.001
%	10.4%	16.9%	50.0%	.6%	
unusual posturing during mealtime	24	9	2	5	< 0.001
%	17.9%	12.7%	33.3%	3.1%	
oral motor problems	11	11	3	4	< 0.001
%	8.2%	15.5%	50.0%	2.5%	

lected symptoms of frequent feediang behavior problems (**Table 5**) and GI dysfunction (**Table 6**). ASD chil- dren often had higher prevalence of (frequency >50% of the time) constipation (30% vs. 4%, p < 0.001, OR = 8.1, CI = 3.5 - 19), soiling (22% vs. 2%, p < 0.001, OR = 6.7, CI = 2.7 - 17), and failure to thrive (22% vs. 7%, p < 0.001, OR = 4.5, CI = 2.1 - 9.4). Higher proportions of ASD children were or had been on a restrictive diet (24%) compared to the controls (9%) (p < 0.006).). Regression models additionally revealed that having been on at least one restrictive diet was associated with increased the odds of constipation (OR = 3.38, CI = 1.14 - 10.04, p = 0.029).

There were no significant differences in abdominal pain, reflux, or other gastrointestinal pathology between the two study groups (**Table 6**).

Duration of feeding problems: When ASD or control children exhibited unusual mealtime preferences and behaviors; these mostly were long term (lasted >6 months).

## 4. DISCUSSION

In accord with several previous studies, our study re-

veals important new information about the high prevalence, frequency and duration of feeding problems, mealtime misbehaviors, and GI dysfunction in children with Asperger syndrome and PDD-NOS (ASD). The study design addresses and cures some of the criticism of previous published studies of gastrointestinal dysfunction in children with autism. This manuscript contains information only about AS and PDD-NOS and excludes the large category of classic autism. Parents of children with ASD are often accurate in diagnosing autism based on Internet-implemented parent report [22]. We accepted only children who had diagnostic criteria for AS or PDD-NOS outlined by the DSM-IV-R manual. We excluded from analysis all survey responses in which the diagnosis of AS or PDD-NOS was not made by professionals (see Survey instrument in appendix). We did not obtain verification of the diagnosis of AS or PDD-NOS by independent review of the child's medical records or by administration of standardized diagnostic tests for AS or PDD-NOS.

Is the diagnosis of AS or PDD-NOS accurate? Should the diagnosis for a substantial percentage of participants with ASD be erroneous, we are at a loss to account for

Faading Problems/Pabavior	Children v	Children with ASD		Controls		Logistic regression odds	Р
Feeding Problems/Behavior	$n = 211  \% \qquad n = 160  \% \qquad \text{exact test}$		ratio (95% CI)	P			
Unusual food preferences	127	60%	6	4%	0.000	38.4 (15.4 - 95.8)	0.000
Dislike of new foods	109	52%	9	6%	0.000	22.2 (9.4 - 52.8)	0.000
Fear of new foods	126	60%	20	13%	0.000	11.3 (6.1 - 21)	0.000
Eating non-food items (Pica)	23	11%	2	1%	0.000	19 (2.4 - 152)	0.006
Disruptive family meal-time	74	35%	7	4%	0.000	9.9 (4 - 24.7)	0.000
behaviors							
Unusual posturing & meals	35	17%	5	3%	0.000	7.8 (2.5 - 23.7)	0.000
Oral-motor problems	25	12%	4	3%	0.001	5.7 (1.5 - 21)	0.009

Table 5. Frequent feeding/behavior problems during meals.

Table 6. Frequent occurrence (<50% of time) of GI dysfunction.

Control totical Symptom	Children v	Children with ASD		Controls		Logistic regression odds	Р
Gastrointestinal Symptom	n = 211	%	n = 160	%	% exact test	ratio (95 % CI)	P
Constipation	62	29%	9	6%	0.000	8.1 (3.5 - 19)	0.000
Soiling	53	25%	7	4%	0.000	6.7 (2.7 - 17)	0.000
Vomiting	16	8%	5	3%	0.073	1.9 (0.5 - 6.9)	0.305
Diarrhea	24	11%	4	3%	0.001	3.9 (1 - 14.8)	0.043
Abdominal Pain	18	9%	6	4%	0.087	2 (0.7 - 6.3)	0.220
Failure To Thrive	51	24%	10	6%	0.000	4.5 (2.1 - 9.4)	0.000
Any Diet Restriction	52	25%	12	8%	0.000	3.1 (1.4 - 7.1)	0.006
Any Food Allergy	<u>52</u>	<u>25%</u>	<u>21</u>	<u>13%</u>	<u>0.006</u>	2.4 (1.2 - 4.5)	<u>0.009</u>
Celiac Disease	9	4%	2	1%	0.703	2.1 (0.2-19)	

the large differences between subjects and sibling controls in gender ratio, achievement of developmental milestones, feeding problems, and gastrointestinal complaints.

Strengths of this survey study include: 1) posting the survey on line in a parallel, split-screed format with questions about children 3 - 12-years old with AS or PDD-NOS on the left side of the split screen, and questions relating to the sibling control on the right side; 2) the wide geographic distribution (no state contributed more than 30% of the U.S. total) and responses from a large number of small towns and cities; 3) Canadian participation; 4) sibling controls; 5) specific developmental and social milestones, and data collection detailing frequency and duration of mealtime feeding problems and GI dysfunction.

Self-criticism of survey methodology: We excluded parents who are not members of ASD support groups. We admittedly captured respondents who express strong opinions on the subject, respondents with high socioeconomic status, and those who are computer literate.

This age range (3 - 12-year old) was selected because based on our assumptions that: 1) high-functioning autism is infrequently diagnosed before the age of 3, 2) feeding patterns and behaviors of children frequently mature after age three years and tend to remain relatively stable until adolescence, 3) eating patterns of children over 12-years are difficult to monitor due to significant amount of time spent outside home.

The survey instrument was developed based on our review of the literature and our own clinical experiences, as well as using comments and suggestions from parents and developmental pediatricians. We did not undertake formal testing of the survey instrument to assess its construct validity and reliability.

The mean age of diagnosis of children with PDD-NOS (4.4 years), was significantly younger than the mean age at diagnosis of the Asperger Syndrome group (7.7 years). This may not be a weakness of the study. Children with PDD-NOS have many more deficits in language and communication and the delay in language acquisition attracts the attention of parent, extended family, and physician. The diagnosis of Asperger Syndrome is usually made later than that of PDD-NOS because language delay is not so severe.

We did not include a formal standardized diagnostic test for Asperger syndrome to keep the time to complete the questionnaire relatively short.

In agreement with results of our study, Olmstead County children with ASD were more likely to manifest feeding issues, food selectivity and constipation [21]. In that study, as in ours, there was no evidence of an increase in celiac disease in ASD children compared to the control group. There are no data, however, to ascertain whether the study group in the Olmstead county Minnesota, study had acute, chronic, or some combination of GI dysfunction [21]. We also do not know about the specifics of "strange feeding issues and/or food selectivity" in that study.

In our survey, more than 52 children (25%) in the AS/PDD-NOS group had been on (or currently are on) restricted diets, most often, casein-free or gluten-free, (p < 0.001) compared to the sibling control group (OR = 3.1, CI = 1.4 - 7.1). Only 1% of those children on a gluten-free diet had a biopsy-proven diagnosis of celiac disease. A multidisciplinary panel of experts recently reviewed the medical literature on the diagnostic evaluation and management of GI problems in children with ASD [23]. Statement 12 of their consensus notes: "available research data do not support the use of a casein-free diet, a gluten-free diet, or combined gluten-free, casein-free (GFCF) diet as a primary treatment for individuals with ASDs."

### **5. CONCLUSIONS**

In a North American on-line survey of many parent support groups for ASD children, children age 3 - 12 years with Asperger syndrome and PDD-NOS have a higher prevalence of abnormal feeding behaviors and gastrointestinal dysfunction compared to their non-ASD siblings. Asperger and PDD-NOS groups were similar in the number and frequency and duration of feeding problems, disruptive mealtime misbehavior, and GI dysfunction.

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#### **APPENDIX**

#### SURVEY INSTRUMENT

#### \*\*SURVEY OF FEEDING AND OTHER DIGESTIVE PROBLEMS IN CHILDREN WITH AUTISM SPECTRUM DISORDERS

By filling out the following survey, you can help pediatricians and other health professionals learn more about certain problems in children with <u>autism spectrum disorders (ASDs</u>). Such problems include unusual food preferences; aversion to certain food colors, textures, and types; ingestion of non-food items; very restricted choices of foods; special diets; sensory processing disorders; oral-motor swallowing problems; vomiting, diarrhea, or constipation; and symptoms of gastroesophageal reflux (GERD) and its complications, such as erosive esophagitis, and food allergies.

Questions in Column "A" pertain to your child with ASD when he/she was <u>ages 3 - 12 years</u>, even if he/she is older now. In Column "B", we ask the same questions for a sibling of your ASD child, closest to him/her in age. Please check the applicable box below and follow the instructions.

I have at least one child with ASD and at least one child who is ASD-free	$\rightarrow$	Complete both columns "A" and "B"
I have at least one child with ASD, and no children who are ASD-free	$\rightarrow$	Complete column "A" only
I have no children with ASD, and at least one child who is ASD-free	$\rightarrow$	Complete column "B" only

#### Please FILL IN the blanks or CHECK the best choice of the following questions:

	Column A Child with Autistm Spectrum Disorder	Column B Child without Autism Spectrum Disorder (control child)
Please provide the last 4 digits of your phone number for tracking purposes.		
City and state of your home		
Current age and gender of your child	years 🔲 Male 🗌 Female	years 🗌 Male 🗌 Female
What is your child's diagnosis? ( <i>Please check all that apply</i> )	<ul> <li>Autism</li> <li>Pervasive developmental disorder, NOS</li> <li>Sensory integration disorder</li> <li>Asperger syndrome</li> <li>Static encephalopathy</li> <li>Other (please specify)</li> </ul>	Child without Autistic Spectrum Disorder → Proceed to the next question
Age at the time of diagnosis	years	Child without Autistic Spectrum Disorder $\rightarrow$ Proceed to the next question
Was the diagnosis made by a child neurologist, child psychiatrist, psy- chologist, general pediatrician, family physician, or developmental pediatric- cian?	<ul> <li>☐ Yes</li> <li>☐ No (who diagnosed your child?</li> <li>☐ Uncertain</li> </ul>	Child without Autistic Spectrum Disorder → Proceed to the next question
Check <b>all</b> that apply to your child	<ul> <li>Met developmental milestones</li> <li>Speaking and understanding appropriately by 4 years of age.</li> <li>Never spoke fluently</li> <li>Difficulty with sustained meaningful interactive play with same-age child by the age of 4 years</li> <li>Unusual mannerisms or demanding same routine over and over</li> </ul>	<ul> <li>a. ☐ Met developmental milestones</li> <li>b. ☐ Speaking and understanding appropriately by 4 years of age.</li> <li>c. ☐ Never spoke fluently</li> <li>d. ☐ Difficulty with sustained meaningful interactive play with same-age child by the age of 4 years</li> <li>e. ☐ Unusual mannerisms or demanding same routine over and over</li> </ul>
Does (did) your child have any of the following neurological/developmental/ genetic conditions? ( <i>Please check all that apply</i> )	<ul> <li>Seizures</li> <li>Down syndrome</li> <li>Hearing disability</li> <li>Mental retardation</li> <li>Other (please specify)</li> <li>Not applicable</li> </ul>	<ul> <li>□ Seizures</li> <li>□ Down syndrome</li> <li>□ Hearing disability</li> <li>□ Mental retardation</li> <li>□ Other (please specify)</li> <li>□ Not applicable</li> </ul>

Does (did) your child have any other medical conditions?	Yes (please specify No Uncertain	)	a. ☐ Yes (please specify b. ☐ No c. ☐ Uncertain	/)
At what age did your child learn to use spoon/fork?	years 🔲 not yet usi	ng spoon / fork	years 🔲 not yet usi	ng spoon / fork
Restricted diet at ages 3 - 12 years? ( <i>Please check all that apply</i> )	<ul> <li>a. Gluten-free</li> <li>b. Soy-free</li> <li>c. Dairy (casein)-free</li> <li>d. Carbohydrate diet</li> <li>e. Candida diet</li> </ul>	h. 🔲 No	<ul> <li>a. Gluten-free</li> <li>b. Soy-free</li> <li>c. Dairy (casein)-free</li> <li>d. Carbohydrate diet</li> <li>e. Candida diet</li> </ul>	h. 🔲 No
Duration of typical dinnertime with family at ages 3 - 12 years?	a. □ ≤30 minutes b. □ 31 - 45 minutes c. □ 46 - 60 minutes	d. □ 61 - 90 minutes e. □ >90 minutes	a. □ ≤30 minutes b. □ 31 - 45 minutes c. □ 46 - 60 minutes	d. □ 61 - 90 minutes e. □ >90 minutes
Marked preference for specific food colors, shapes, textures, presentation, or specific arrangement of food on the plate at ages 3 - 12 years? ( <i>please</i> <i>answer both Frequency and Duration</i> <i>headings</i> )	a. $\square$ Never b. $\square$ Rarely (<10%) c. $\square$ Sometimes	Duration         a.       Never         b.       <6 months	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months
Insistence on eating with specific uten- sils/dishes at ages 3 - 12 years? ( <i>please</i> <i>answer both Frequency and Duration</i> <i>headings</i> )	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months	Frequency         a.       Never         b.       Rarely (<10%)	Duration         a.       Never         b.       <6 months
Marked aversion/fear of specific food colors, shapes, textures, presentation, or specific arrangement of food on the plate at ages 3 - 12 years? ( <i>please</i> <i>answer both Frequency and Duration</i> <i>headings</i> )	a. $\square$ Never b. $\square$ Rarely (<10%) c. $\square$ Sometimes	Duration         a.       Never         b.       <6 months	Frequency         a.       Never         b.       Rarely (<10%)	Duration         a.       Never         b.       <6 months
Fear of ingestion of <u>new</u> foods at ages 3 - 12 years? ( <i>please answer both</i> <i>Frequency and Duration headings</i> )		Duration         a.       Never         b.       <6 months	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months
Ingestion of non-food items, such as paper, string, dirt, hair, at ages 3 - 12 years? ( <i>please answer both Frequency</i> <i>and Duration headings</i> )	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months
Poor social mealtime behaviors (would not sit with family, temper tantrum during meal time, throwing food) at ages 3 - 12 years? ( <i>please answer both</i> <i>Frequency and Duration headings</i> )	b. ☐ Rarely (<10%) c. ☐ Sometimes	Duration         a.       Never         b.       <6 months	Frequency         a. □ Never         b. □ Rarely (<10%)	Durationa.Neverb. $\leq 6$ monthsc. $\subseteq 6$ mo - 1 yeard. $\geq 1$ yeare.Uncertain

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Frequency Frequency **Duration Duration** a. Never b. Rarely a. Never b. Rarely (<10%) Behavior outbursts during school a. <u>Never</u> b. <u><</u> <6 mo a. 
Never
b. 
</br> lunch, requiring intervention by the b. Rarely (<10%) <6 months <6 months teacher or other school personnel at c. 
Sometimes c. Sometimes c. □ 6 mo – 1 year c. 🗌 6 mo -1 year ages 3 - 12 years? (please answer both (10% - 49%) (10% - 49%) d. 🔲 >1 year d. 🔲 >1 year Frequency and Duration headings) d. Often (>50%) d. Often (>50%) e. 🗌 Uncertain e. 🗌 Uncertain e. 🔲 Uncertain e. 🗌 Uncertain Frequency Frequency **Duration** Duration Never a. 🗌 Never a. Eating at the same table with other a. Never a.  $\square$  Never  $\square$  Rarely (<10%) b.  $\square$  Rarely (<10%) b children who do not have behavioral b. 🗌 <6 months b. 🗌 <6 months □ Sometimes c. 
Sometimes problems? (please answer both Frec.  $\square$  6 mo -1 year d.  $\square$  >1 year c.  $\square$  6 mo -1 year d.  $\square$  >1 year (10% - 49%) (10% - 49%) quency and Duration headings) d. Often (>50%) d. Often (>50%) e. 🔲 Uncertain e. 🔲 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain Frequency Frequency Duration Duration Unusual posturing (neck or trunk turna. 🗌 Never a. 🗌 Never a. Never a. 
Never ing/bending/arching) during or after b. Rarely (<10%) b. Rarely (<10%) b.  $\Box$  <6 months b.  $\Box$  <6 months meals at ages 3 - 12 years? (please c. ☐ Sometimes c. 
Sometimes c.  $\square$  6 mo – 1 year d.  $\square$  >1 year c. ☐ 6 mo -1 year d. ☐ >1 year answer both Frequency and Duration (10% - 49%) (10% - 49%) d.  $\Box$  Often (>50%) d Often (>50%) headings) e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain Frequency Frequency Duration Duration Never
Rarely (<10%) a. Never b. Rarely (<10%) Oral-motor coordination problems (difa. a. 🗌 Never a. 🗌 Never culty moving solid food inside mouth) b. b.  $\Box$  <6 months b.  $\Box$  <6 months at ages 3 - 12 years? (please answer c. Sometimes c. 
Sometimes c. 🗌 6 mo - 1 year c. 🗌 6 mo - 1 year both Frequency and Duration head-(10% - 49%)(10% - 49%)d. >1 year d. >1 year d. 🗋 Often (>50%) d. Often (>50%) ings) e. 🗌 Uncertain e. 🗌 Uncertain e. 🗍 Uncertain e. 🗍 Uncertain At what age did your child get toilet training for daytime bowel move-\_\_\_\_ years 🔲 not yet toilet trained \_\_\_\_ years 🔲 not yet toilet trained ments? Frequency Frequency **Duration Duration** Never Never a. a. 🗌 Never a. 🗌 Never Rarely (<10%) b.  $\square$  Rarely (<10%) Vomiting at ages 3 - 12 years? (please b. b. 🗌 <6 months b. 🗌 <6 months answer both Frequency and Duration c. □ Sometimes c. 
Sometimes c.  $\square$  6 mo - 1 year d.  $\square$  >1 year c. ☐ 6 mo - 1 year d. ☐ >1 year (10% - 49%)headings) (10% - 49%)d. Often (>50%) d. Often (>50%) e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain Frequency Frequency **Duration Duration** Never □ Never □ Rarely (<10%) Never a. a. Diarrhea (more than 3 watery bowel a. 🗌 Never a. 🗌 Never Rarely (<10%) b. b. b. 🗌 <6 months b. 🗌 <6 months movements per day) at ages 3 - 12 □ Sometimes c. 
Sometimes c. years? (please answer both Frequency c. 🗌 6 mo - 1 year c. 🗌 6 mo - 1 year (10% - 49%) (10% - 49%) d. 🗌 >1 year and Duration headings) d. □ >1 year Often (>50%) d. 🗋 Often (>50%) d. e. 🔲 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain Frequency Frequency **Duration Duration** Never
Rarely (<10%) a. Never b. Rarely (<10%) a.  $\square$  Never b.  $\square$  <6 months a. □ Never b. □ <6 months Constipation (more than 3 days beb. tween bowel movements) at ages 3 -☐ Sometimes ☐ Sometimes c. C. c. 🗌 6 mo - 1 year c. 🗌 6 mo - 1 year 12 years? (please answer both Fre-(10% - 49%)(10% - 49%)quency and Duration headings) d. □ >1 year d. □ >1 year d. ☐ Often (>50%) e. ☐ Uncertain d. 🗋 Often (>50%) e. 🗌 Uncertain e. 🗌 Uncertain e. 🗌 Uncertain Frequency Frequency Duration Duration Never a. 🗌 Never a. a. 🗌 Never a. 🗌 Never Soiling in underpants or withholding b. Rarely (<10%) b. Rarely (<10%) <6 months <6 months b. b. □ Sometimes stool? (please answer both Frequency Sometimes c. c. c. 🔲 6 mo - 1 year c. 🔲 6 mo - 1 year (10% - 49%) and Duration headings) (10% - 49%) d. 🗌 >1 year d. □ >1 year Often (>50%) d. 🔲 Often (>50%) d e. 🗌 Uncertain e. 🗌 Uncertain Uncertain Uncertain

e.

e.

Inadequate/under weight or failure to thrive at ages 3 - 12 years?	a. ☐ Yes b. ☐ No c. ☐ Uncertain		a. Yes b. No c. Uncertain	
Difficulty swallowing solid food at ages 3 - 12 years? ( <i>please answer both Frequency and Duration headings</i> )		Duration         a.       Never         b.       <6 months	Frequency         a. □ Never         b. □ Rarely (<10%)	Duration         a.       Never         b.       <6 months
Reflux / indigestion/ GERD/ esophagi- tis at ages 3-12 years? (please answer both Frequency and Duration head- ings)	Frequency         a. □ Never         b. □ Rarely (<10%)         c. □ Sometimes         (10% - 49%)         d. □ Often (>50%)         e. □ Uncertain	Duration         a.       Never         b.       <6 months         c.       6 mo - 1 year         d.       >1 year         e.       Uncertain	Frequency         a. □ Never         b. □ Rarely (<10%)         c. □ Sometimes         (10% - 49%)         d. □ Often (>50%)         e. □ Uncertain	Duration         a.       □       Never         b.       □       <6 months         c.       □       6 mo - 1 year         d.       □       >1 year         e.       □       Uncertain
If you selected "b", "c", or "d" in the previous question, what tests did your child have a test to confirm Reflux/ indigestion/ GERD/ esophagitis at the age of 3 - 12 years? ( <b>please check all that apply</b> )	<ul> <li>a. Barium swallow</li> <li>b. pH probe</li> <li>c. Endoscopy</li> <li>d. Biopsy</li> <li>e. Videofluoroscopy</li> </ul>	f. Other g. No tests h. Not applicabl. i. Uncertain	<ul> <li>a. Barium swallow</li> <li>b. pH probe</li> <li>c. Endoscopy</li> <li>d. Biopsy</li> <li>e. Videofluoroscopy</li> </ul>	f. Dother g. No tests h. Not applicabl. i. Uncertain
Food allergies at ages 3 - 12 years? (please check all that apply)	a. ☐ Milk b. ☐ Eggs c. ☐ Citrus d. ☐ Wheat	f. ☐ Yeast g. ☐ Corn h. ☐ Other i. ☐ No allergies j. ☐ Uncertain	a. D Milk b. Eggs c. Citrus d. Wheat	f. Yeast g. Corn h. Other i. No allergies j. Uncertain
Abdominal pain requiring a doctor visit at ages 3 - 12 years? (please an-	Frequency a. □ Never b. □ Rarely (<10%)	Duration           a.         □           Never           b.         □           <6	Frequency           a.         □           Never           b.         □           Rarely (<10%)	<b>Duration</b> a. ☐ Never b. <u></u> <6 months
swer both Frequency and Duration headings)	<ul> <li>c. ☐ Sometimes (10% - 49%)</li> <li>d. ☐ Often (&gt;50%)</li> <li>e. ☐ Uncertain</li> </ul>	c. ☐ 6 mo - 1 year d. ☐ >1 year e. ☐ Uncertain	(10% - 49%) d. □ Often (>50%) e. □ Uncertain	c. ☐ 6 mo - 1 year d. ☐ >1 year e. ☐ Uncertain
	(10% - 49%) d. □ Often (>50%) e. □ Uncertain a. □ Yes	d. 🗌 >1 year	(10% - 49%) d. 🔲 Often (>50%)	d. 🔲 >1 year
<i>headings</i> ) Celiac disease, proven by blood tests or by intestinal biopsy at ages 3 - 12	(10% - 49%) d. □ Often (>50%) e. □ Uncertain a. □ Yes b. □ No	d. 🗌 >1 year	(10% - 49%) d. □ Often (>50%) e. □ Uncertain a. □ Yes b. □ No	d. 🔲 >1 year
<i>headings</i> ) Celiac disease, proven by blood tests or by intestinal biopsy at ages 3 - 12 years? Eosinophilic esophagitis proven by	(10% - 49%)         d.       Often (>50%)         e.       Uncertain         a.       Yes         b.       No         c.       Uncertain	d. 🗌 >1 year	(10% - 49%) d.  Often (>50%) e.  Uncertain a.  Yes b.  No c.  Uncertain a.  Yes b.  No c.  Uncertain a.  Yes b.  No c.  Uncertain a.  Yes b.  No c.  Uncertain a.  Yes	d. 🔲 >1 year
<ul><li>headings)</li><li>Celiac disease, proven by blood tests or by intestinal biopsy at ages 3 - 12 years?</li><li>Eosinophilic esophagitis proven by biopsy at ages 3 - 12 years?</li><li>Diseases of small or large intestine at</li></ul>	(10% - 49%)         d. □ Often (>50%)         e. □ Uncertain         a. □ Yes         b. □ No         c. □ Uncertain         a. □ Yes         b. □ No         c. □ Uncertain         a. □ Yes         b. □ No         c. □ Uncertain         a. □ Yes         b. □ No         c. □ Uncertain         a. □ Zantac         b. □ Prevacid         d. □ Prilosec         e. □ Flagyl	d. 🗌 >1 year	(10% - 49%)         d.       Often (>50%)         e.       Uncertain         a.       Yes         b.       No         c.       Uncertain         a.       Zestac         b.       No         c.       Uncertain         a.       Zantac         b.       Prevacid         d.       Prilosec         e.       Flagyl	d. 🔲 >1 year

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_

Is your child on Medicaid?	yes no	🗌 yes 🗌 no
Estimate the total out-of-pocket (medi- cal, drug, education, P.T., O.T., and speech therapy) expenditures in the year 20012 for your ASD child.	a. ☐ Less than \$1000 b. ] \$1000 - \$5000 c. ] \$6000 - \$10,000 d. ] \$11,000 - \$25,000 e. ] >\$25,000	a. ☐ Less than \$1000 b. ☐ \$1000 - \$5000 c. ☐ \$6000 - \$10,000 d. ☐ \$11,000 - \$25,000 e. ☐ >\$25,000
What is your total household income?	a. □ Less than \$25,000 b. □ \$25,000 - \$50,000 c. □ \$50,000 - \$75,000 d. □ > \$75,000	a. ☐ Less than \$25,000 b. ☐ \$25,000 - \$50,000 c. ☐ \$50,000 - \$75,000 d. ☐ > \$75,000

THANK YOU VERY MUCH FOR YOUR TIME AND EFFORT. If you would like to receive a summary of these survey results, please write in your e-mail address \_\_\_\_\_\_.