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Parental Report of Early Autistic Symptoms: Differences in Ages of Detection and Frequencies of Characteristics Among Three Autism-Spectrum Disorders

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Abstract

Parents and caregivers (91.1% mothers; M age=36 years) of 259 children age 10 or younger (82.6% boys; M age=6 years) with autism-spectrum disorders (ASD) responded to a web-based questionnaire regarding the ages at which their children showed 11 symptoms of autism. All symptoms were noticed earlier than the 3 years of age at which diagnosis is usually deemed possible. The percentages of parents who affirmed the presence of various characteristics differed based on their child's type of ASD diagnosis (autism, Asperger's, or PDD-NOS). Mean ages at which parents first noticed autistic characteristics ranged from 10 months to 2.7 years; however, the ages at which parents detected 8 symptoms also differed based on diagnosis. Limitations of this large-sample survey include participation only by families who have access to the internet and a lack of external confirmation of parent-reported diagnoses.

Earlier detection of autism is important for affected children and for their families, as early diagnosis allows children to enter intervention services at younger ages. Those who participate in treatments when they are very young are reported to exhibit more positive outcomes relative to older children with autism undergoing the same interventions (Rogers, 1998). It is no wonder, then, that improvements in diagnostic capabilities, particularly with infants and toddlers, was prioritized as the second-leading area needing investigation at the 1998 National Institute of Health Autism Coordinating Committee, following only the search for a cure for autism (Bristol-Power & Spinella, 1999). Given the importance of early detection, it is necessary to examine those characteristics in children younger than age 3 who were initially viewed as different, delayed, or otherwise unusual and later diagnosed in the autism spectrum. Identification of autism in such young

populations, however, is not a clear-cut task. Current diagnostic criteria, according to the *DSM-IV*, describe behaviours (either present or absent) that are appropriate to consider in preschool-aged and older children; however, these criteria are inappropriate for infants and toddlers simply because toddlers have not yet reached developmental levels at which they can be expected to perform (or not perform) those behaviours. Trained clinicians sometimes identify children under 2 years, yet the behaviours that are critical for the diagnosis have not been clearly recognized or validated (Young & Brewer, 2002).

Perhaps this sense of not knowing what to look for during the first 2 years of life plays a role in clinicians' hesitancy to diagnose autism until age 3 or later. However, some evidence suggests that physicians commonly delay making diagnoses of such autism-spectrum disorders (ASD) among young populations, even when symptoms are present (Bonner & Finney, 1996), and may dismiss parents' concerns and opinions about their children (Schall, 2000). As Gray (1995) described:

> *Even when children experienced severe problems, doctors were reluctant to diagnose a serious disorder because of the child's young age. Parents were commonly told that they were either exaggerating the child's problems, or that the child would 'grow out of it' and develop normally. (p. 108).*

Researchers interested in discovering what autistic symptoms look like in infants and toddlers – as opposed to preschool-aged and older children – have commonly adopted a retrospective methodology. Some have examined home videotapes of children already diagnosed with ASD, specifically focussing on footage during children's first few years, prior to a diagnosis (e.g., Adrien, et al., 1993; Baranek, 1999; Carmagnat-Dubois, et al., 1997; Werner, Dawson, Osterling, & Dinno, 2000; Zakian, Malvy, Desombre, Roux, & Lenoir, 2000). Others have used questionnaires and interviews to ask parents of diagnosed children to recall the unusual behaviours that initially caused them concern and prompted them to seek clinical attention (e.g., Coonrod, Turner, Pozdol, & Stone, 2001; DeGiacomo & Fombonne, 1998; Robins, Fein, Barton, & Green, 2001; Vostanis, et al., 1998; Williams & Ozonoff, 2001; Wimpory, Hobson, Williams, & Nash, 2000). Overall, both methodologies have yielded similar results, with deficits and/or differences between typically developing children and those later diagnosed with ASD commonly noted in the following areas: eye contact, affective behaviours, verbal and physical imitations, joint-attention behaviours, physical movements/ambulation (e.g., rolling over, crawling), use of

gestures, responsiveness to one's name and/or the presence of others, attention-seeking behaviours, social/cooperative play, and language (see Goin & Myers, 2004, for a complete review).

In one recent investigation, retrospective-parent reports were used to identify the core deficit-linked behaviours indicative of autism during the first few years of life (Young, Brewer, & Pattison, 2003). Participants (n = 81) were mailed a questionnaire that contained both (a) an open-ended question asking them to describe their children's behaviours that first caused them concern and (b) a checklist of 33 anomalous behaviours commonly seen in children with autism. Additionally, participants were asked to indicate the age of their children at the time they noticed each reported behaviour. The most frequently cited characteristics within the open-ended question were delayed language (77.8%) at an average age of 18.4 months, no attention to caregiver (34.6%) at an average age of 17.1 months, poor socialization (29.6%) at an average age of 24.8 months, and tantrums/crying (28.4%) at an average age of 18.1 months. Within the closed-ended section, 42.2% to 78.3% of parents cited difficulties with various communication behaviours at average ages of 26.6 to 39.8 months; 42.6% to 100% of parents reported various social and/or play anomalies at average ages of 12.8 to 26.1 months; and 22.5% to 84% of parents cited various stereotyped interests/behaviours at average ages of 19.6 to 29.7 months. Of note is the wide variability in the children and the fact that only one characteristic-preference for playing alone-was reported by 100% of families.

Parents are undoubtedly sensitive to differences in their children's development and are often the first to call the aforementioned symptoms to clinical attention. Several investigations attest to the accuracy and consistency of parents' observations regarding their children's atypical development (e.g., Ireton & Glascoe, 1995; Shulman, 2001; Siegel, Pliner, Eschler, & Elliott, 1988; Stone, Hoffman, Lewis, & Ousley, 1994). Likewise, numerous studies document parents' reporting of their children's autistic-like characteristics during infancy and early toddlerhood (e.g., De Giacomo & Fombonne, 1998; Smith, Chung, & Vostanis, 1994; Vostanis, et al., 1998; Weatherby & Woods, 2003; Williams & Ozonoff, 2001). While this methodology has been criticized because of the potential for parents to remember events incorrectly, validity can be enhanced by focussing on parental reports of younger children, as these parents are not required to remember as far back as are those of teenage or adult children.

It is clear that autism presents as atypical development and behaviour, particularly in the social and communicative domains, among very young

children. Parents commonly note developmental anomalies during their children's second year of life, and some evidence supports detection during the first year. Much of what we have learned about autistic-like behaviours in very young populations, however, has been derived from findings based on small samples-in some instances, fewer than 10 cases per diagnostic group (e.g., Carmagnat-Dubois, et al., 1997). Therefore, one goal of the present investigation was to examine parent reports on the ages at which they identified specific symptoms in their children later diagnosed with an ASD among a large sample, a goal similar to that of Young, Brewer, and Pattison (2003). Different from their work, a second goal was to compare the ages of symptom detection and the types of symptoms noticed by parents of children across the three diagnoses of autism, Asperger's syndrome, or pervasive developmental disorder - not otherwise specified (PDD-NOS). As in Young et al.'s (2003) work, data were only considered from families whose children were 10 years old or younger at the time of the study. This restriction further mandated our collection of a sample large enough to ensure adequate representation for the 3 diagnostic categories; hence, an internet data-collection strategy was chosen. Recent evidence suggests that web-based research yields both samples and findings that are not different from research conducted in a traditional questionnaire manner, and that an advantage of this method is the ability to locate hard to reach populations (Gosling, Vazire, Srivastava, & John, 2004). We sought to answer the following research questions: (a) what is the time span between first-symptom detection and ASD diagnosis, and how might this range differ across ASD groups? (b) are there differences among the three ASD categories in the ages at which parents first notice autistic symptoms? and (c) do parents whose children have different ASD diagnoses affirm the presence of various symptoms at different frequencies?

Method

Participants

The original sample included 378 children with ASD, 305 (80.7%) of whom were male. At the time of the study, their average age was 8.6 years (*SD* = 4.8), with a range from 2 to 36. Mothers provided data in most cases (89.9%), and they described their children as having a diagnosis of autism (65.6%), Asperger's syndrome (19.8%), or PDD-NOS (14.3%); one child had Childhood Disintegrative Disorder. To enhance the validity of retrospective reports, only data for children aged 10 years and younger were considered for the present investigation. Thus, the final sample contained 259 children, with

214 boys (82.6%) and 44 girls (17.0%). Their average age was 6 years (*SD* = 2.2, range = 2 to 10). The most common diagnosis was, again, autism (67.2%), followed by PDD-NOS (16.6%), and Asperger's syndrome (16.2%). More information on focal children can be found in Table 1.

Table 1. Focal Child Demographic Information (n = 259)

Variable /Category	*n (%) or M (SD)*	*Variable /Category*	*n (%)*
Gender		ASD Diagnosis	
Male	214 (82.6%)	Autism	174 (67.2%)
Female	44 (17.0%)	PDD-NOS	43 (16.6%)
Age*		Asperger's	42 (16.2%)
Total	6.0 (2.2)	Diagnosing Professional	
Male	5.9 (2.2)	Specialist**	122 (47.1%)
Female	6.3 (2.2)	Psychologist	58 (22.4%)
Race		Team/Center	28 (10.8%)
White	220 (85.0%)	Psychiatrist	27 (10.4%)
Bi-racial	19 (7.3%)	Other	14 (5.4%)
Hispanic /Latino	8 (3.1%)	Family doctor	6 (2.3%)
Other	5 (1.9%)		
Black	3 (1.2%)		
Asian	2 (0.8%)		
Middle Eastern	2 (0.8%)		

** In years*

*** Most often, a pediatric neurologist or developmental pediatrician.*

Participants in this smaller sample were mothers (n = 126; 91.1%), fathers (n = 22; 8.5%), and 1 grandmother (0.4%) of the children described above. Their mean age was 36 years (*SD* = 6.1; range = 23 to 57) and they had completed, on average, 15.3 years of school (*SD* = 2.4; range = 9 to 26), which was equivalent to the third year of college. Just over half of the families reported incomes of $55,000 or more; the U.S. median income for a family of 4 was $63,278 during the 2001 census. A large percentage of individuals (n = 47, 18.1%) reported family incomes at or greater than $100,000 per year, a number larger than the 14.8% of white families in the 2001 census who reported this high income. Participants represented almost every state in the U.S. (75.3% of respondents were from the U.S.) as well as the countries of Australia, Canada, England, Ireland, and New Zealand (18.9% combined). About 6% did not indicate their locale. The largest

number of parents reported their race as white/Caucasian (n = 226, 87.3%), with 13% of the sample reporting themselves as Hispanic/Latino, Asian, and other ethnicities, as presented in Table 2. The majority of parents were married at the time they completed the questionnaire (n = 212, 81.9%). Because we used a web-based data-collection method that required participant knowledge of and access to computers and the internet, the sample was not representative of all families with a child with autism; in particular, minorities and lower-income families were underrepresented.

Table 2. Parent Demographic Information (n = 259)

Variable /Category	*n (%) or M (SD)*	*Variable /Category*	*n (%)*
Gender		Race	
Female	235 (90.7%)	White	226 (87.3%)
Male	22 (8.5%)	Hispanic/Latino	10 (3.9%)
Age*		Asian	7 (2.7%)
Total	36.0 (6.1)	Black	4 (1.5%)
Female	35.6 (6.1)	Biracial	4 (1.5%)
Male	39.8 (5.5)	Other	3 (1.2%)
Education*		Middle Eastern	2 (0.8%)
Total	15.3 (2.4)	Native American	1 (0.4%)
Female	15.2 (2.4)	Marital Status	
Male	16.2 (2.6)	Married	212 (81.9%)
Income**		Single	17 (6.6%)
<$10	4 (1.5%)	Divorced	16 (6.2%)
>$10 to $25	24 (9.3%)	Separated	10 (3.9%)
>$25 to $40	47 (18.1%)	Widowed	2 (0.8%)
>$40 to $55	38 (14.7%)	Locale	
>$55 to $70	45 (17.4%)	U.S.	195 (75.3%)
>$70 to $100	45 (17.4%)	Canada	18 (7.0%)
>$100	47 (18.1%)	England/Ireland	18 (7.0%)
Relation		Australia /New Zealand	13 (5.0%)
Mother	236 (91.1%)		
Father	22 (8.5%)		
Grandmother	1 (0.4%)		

** In years*

*** In thousands of U.S. dollars per year*

Instrument

Data were collected anonymously through a web-based questionnaire designed to measure parents' perceptions of the development of autism in their children. The creation of the questionnaire followed Dillman's (2000)

recommendations regarding simplicity of web-based questions and question formats. We also sought the input of 2 mothers of children with autism to ensure that our questions were clearly stated and that we were not excluding viable answer choices. Parents indicated the months/years at which they first noted the following 11 symptoms of autism in their children: slowness in meeting motor milestones (e.g., rolling over, crawling, walking), failure to attach to a caregiver, failure to use/respond to gestures (e.g., waving, pointing), lack of responsiveness (e.g., to name, suggestions), lack of social smiling, language delay, lack of eye contact, unusual interaction with or attachment to objects, lack of imaginative or pretend play, unusual physical behaviours (e.g., persistent rocking, hand-flapping), and not playing with other children. These particular characteristics are commonly noted in the literature on early symptoms of autism during the first few years of life and were selected because of their relatedness to the core-deficits criteria used to screen for autism in very young populations.

Procedure

Study advertisements appeared in the newsletters, webpages, and e-mail list-serves of autism-related organizations that agreed to cooperate with our study. More than 220 such organizations (e.g., local chapters for the Autism Society of America, National Autistic Society) in the U.S. and 7 other English-speaking countries were contacted. Once families located the questionnaire website, they were provided with a description of the investigation and informed-consent information. All submitted responses were automatically transferred to a database for later statistical analyses. The study protocol was approved by the university IRB and participant consent was denoted by submission of a completed questionnaire. Families received no payment or other benefit through cooperating with the study.

Results

Considered together, the average age at which children were diagnosed within the autism spectrum was 3.5 years (SD = 1.6, range = 1.2 to 9). However, this age varied significantly by diagnosis, with children with autism diagnosed at the youngest age (M = 3.0 years, SD = 1.1), followed by those with PDD-NOS (M = 3.5 years, SD = 1.5), and those with Asperger's syndrome (M = 5.7 years, SD = 1.8), $F(2, 252) = 74.763$, $p < 0.001$. Although boys consistently received diagnoses at earlier ages than did girls, a significant difference between the sexes was only evidenced for the PDD-NOS group (see Table 3).

Table 3. Means, Standard Deviations, and One-Way ANOVA's for Effects of Diagnostic Group and Gender on Age at Diagnosis

	Male		*Female*			
	M (SD)	*n*	*M (SD)*	*n*	*ANOVAF (df)*	*p*
Type of ASD						
Autism	3.0 (1.0)	143	2.9 (1.1)	29	0.262 (1, 170)	0.609
PDD-NOS	3.2 (1.0)	35	5.0 (2.2)	8	13.191 (1, 41)	.001**
Asperger's	5.7 (1.8)	34	5.5 (1.9)	6	0.073 (1, 38)	0.789

** *denotes significance.*

Several characteristics were noted by some parents as present within the first few months of life, yet within diagnostic groups, the earliest average age at which an unusual behaviour was noted ranged from 10 months to 1.2 years (14 months), while the oldest average age at which an unusual behaviour was noted ranged from 1.9 years (23 months) to 2.7 years. To estimate the length of time from early-symptom detection to diagnosis, we subtracted the youngest and oldest average ages for symptom identification within each diagnostic group from the average age of diagnosis for that ASD. On average, parents of children diagnosed with autism experienced a delay of 13 to 24 months between symptom detection and diagnosis, parents of children diagnosed with PDD-NOS, a delay of 14 to 32 months, and parents of children diagnosed with Asperger's syndrome, a delay of 3 to 4.5 years.

Eight of the 11 early symptoms were indicated by more than 50% of the sample as being different or delayed in their children. The most common characteristic was language delay (n = 221, 85.3%), detected by parents at an average age of 1.7 years (20 months). The two characteristics that were least frequently reported – "failure to attach to caregiver" (22%) and "slowness in meeting motor milestones" (33.2%) – were those that parents reported noticing at the youngest average ages, 1.2 years (14 months) and 1.1 years (13 months), respectively. To assess potential differences in ages of symptom identification among the three ASD-diagnoses, we computed one-way analyses of variance (ANOVAs) for each of the 11 early characteristics, applying the Bonferroni correction to guard against spurious findings. Parents whose children were diagnosed with autism reported noticing "lack of social smiling" and "unusual physical behaviours" at significantly younger ages relative to parents of children with either PDD-NOS or Asperger's syndrome. Parents of children diagnosed with Asperger's syndrome indicated the following 5 behaviours at significantly older ages than did parents in the autism and PDD-NOS groups: "lack of responsiveness"; "failure to use or respond to gestures"; "language delay";

"lack of imaginative or pretend play"; and "not playing with other children." For only 1 item – "lack of eye contact" – were there significant differences in age of detection among all 3 groups, with parents of children with autism reporting this symptom at the earliest age, followed by parents of children diagnosed with PDD-NOS, and then parents of children with Asperger's syndrome. More information is provided in Tables 4 and 5.

Table 4. Ages in Years at Which Early Characteristics Were First Detected

Characteristic /Diagnosis	*Mean (SD)*	*Median*	*Mode*	*Range*	*n (%)*
1. Lack of eye contact					
Autism	1.5 (0.7)	1.5	1.5	0.1-3.7	135 (**77.6%**)
Asperger's	2.5 (1.6)	2.1	3.0	0.2-8.5	28 (**66.7%**)
PDD-NOS	2.0 (0.8)	1.8	1.5	0.2-4.7	29 (**67.4%**)
2. Lack of social smiling					
Autism	1.3 (0.7)	1.4	1.5	0.1-3.0	81 (46.6%)
Asperger's	2.4 (1.3)	2.0	2.0	0.5-5.0	13 (31.0%)
PDD-NOS	1.9 (0.7)	1.9	1.8	0.3-2.7	11 (25.6%)
3. Failure to attach to caregiver					
Autism	1.2 (0.7)	1.0	1.0	0.2-3.0	43 (24.7%)
Asperger's	1.2 (0.8)	1.5	2.0	0.2-2.0	9 (21.4%)
PDD-NOS	0.8 (0.5)	0.5	0.5	0.3-1.4	5 (11.6%)
4. Slowness in meeting motor milestones					
Autism	1.0 (0.6)	0.9	0.5	0.3-3.4	60 (34.5%)
Asperger's	1.4 (1.2)	0.7	0.5	0.1-4.0	13 (31.0%)
PDD-NOS	1.2 (1.1)	1.0	0.5	0.2-4.2	13 (30.2%)
5. Lack of responsiveness					
Autism	1.5 (0.6)	1.5	1.5	0.1-3.7	142 (**81.6%**)
Asperger's	2.2 (0.9)	2.0	2.0	0.8-5.0	19 (45.2%)
PDD-NOS	1.8 (0.7)	1.8	2.0	0.5-4.0	28 (**65.1%**)
6. Failure to use/respond to gestures					
Autism	1.5 (0.6)	1.5	1.0	0.1-3.7	128 (**73.6%**)
Asperger's	2.5 (1.2)	2.0	2.0	1.0-5.0	16 (38.1%)
PDD-NOS	1.5 (0.5)	1.5	1.5	0.5-2.5	29 (**67.4%**)
7. Language delay					
Autism	1.6 (0.6)	1.5	1.5	0.2-4.0	161 (**92.5%**)
Asperger's	2.2 (1.1)	1.8	1.5	0.5-5.0	20 (47.6%)
PDD-NOS	1.8 (0.8)	1.5	1.5	0.5-4.0	40 (**93.0%**)

cont'd

Table 4. (cont'd)

Characteristic /Diagnosis	*Mean (SD)*	*Median*	*Mode*	*Range*	*n (%)*
8. Unusual physical behaviours					
Autism	1.7 (0.7)	1.6	2.0	0.3-4.0	110 (**63.2%**)
Asperger's	2.4 (1.2)	2.0	2.0	0.7-4.7	27 (**64.3%**)
PDD-NOS	2.3 (0.9)	2.0	2.0	1.0-5.0	22 (**51.2%**)
9. Unusual interaction with/attachment to objects					
Autism	1.7 (0.9)	1.5	1.5	0.3-7.0	117 (**67.2%**)
Asperger's	2.4 (1.7)	2.0	2.0	0.1-9.5	25 (**59.5%**)
PDD-NOS	2.0 (0.8)	2.0	2.0	0.5-4.0	19 (44.2%)
10. Lack of imaginative/pretend play					
Autism	1.9 (0.7)	2.0	2.0	0.2-4.0	134 (**77.0%**)
Asperger's	2.5 (0.9)	2.5	2.0	0.5-4.0	23 (**54.8%**)
PDD-NOS	1.9 (0.6)	1.8	2.0	0.5-3.0	27 (**62.8%**)
11. Not playing with other children					
Autism	1.9 (0.7)	2.0	2.0	0.2-4.0	143 (**82.2%**)
Asperger's	2.7 (1.1)	2.0	2.0	1.0-5.0	27 (**64.3%**)
PDD-NOS	2.1 (0.7)	2.0	2.0	0.5-4.0	26 (**60.5%**)

Note. Bolded items are those for which more than half of the cases within a diagnostic category exhibited the given characteristic.

Table 5. Means, Standard Deviations, and One-Way ANOVAs for Ages of Symptom Detection by Diagnostic Category

	Autism	*Asperger's*	*PDD-NOS*		*ANOVA*	
Variable	*M (SD)*	*M (SD)*	*M (SD)*	*F*	*df*	*p*
1. Lack of eye contact	1.5 (0.7)*	2.5 (1.6)*	2.0 (0.8)*	14.634	(2, 189)	< **.001**
2. Lack of social smiling	1.3 (0.7)*	2.4 (1.3)	1.9 (0.7)	12.006	(2, 102)	< **.001**
3. Failure to attach to caregiver	1.2 (0.7)	1.2 (0.8)	0.8 (0.5)	0.980	(2, 54)	0.382
4. Slowness in meeting motor milestones	1.0 (0.6)	1.4 (1.2)	1.2 (1.1)	1.359	(2, 83)	0.262
5. Lack of responsiveness (e.g., to name)	1.5 (0.6)	2.2 (0.9)*	1.8 (0.7)	11.924	(2, 186)	< **.001**

cont'd

Table 5. (cont'd)

Variable	*Autism M (SD)*	*Asperger's M (SD)*	*PDD-NOS M (SD)*	*F*	*ANOVA df*	*p*
6. Failure to use/respond to gestures	1.5 (0.6)	2.5 (1.2)*	1.5 (0.5)	17.320	(2, 170)	< **.001**
7. Language delay	1.6 (0.6)	2.2 (1.1)*	1.8 (0.8)	8.272	(2, 218)	< **.001**
8. Unusual physical behaviours	1.7 (0.7)*	2.4 (1.2)	2.3 (0.9)	9.275	(2, 156)	< **.001**
9. Unusual interaction with/attachment to objects	1.7 (0.9)	2.4 (1.7)	2.0 (0.8)	4.768	(2, 158)	0.010
10. Lack of imaginative or pretend play	1.9 (0.7)	2.5 (0.9)*	1.9 (0.6)	6.124	(2, 181)	**0.003**
11. Not playing with other children	1.9 (0.7)	2.7 (1.1)*	2.1 (0.7)	14.122	(2, 193)	< **.001**

Note. The "" indicates ages that are significantly different from both remaining groups. Bolded p-values indicate those remaining significant with the Bonferroni correction applied, p < .0045.*

To understand if parents identified symptoms at different frequencies across the three diagnostic groups, we computed chi-square analyses for each of the 11 characteristics. Significantly more parents in the autism group noted "lack of social smiling" than did parents of children with Asperger's syndrome, who, in turn, reported this characteristic at a higher rate than did parents of children with PDD-NOS. "Lack of responsiveness" and "lack of imaginative or pretend play" were more often reported among parents in the autism group relative to those in the PDD-NOS group, who reported these characteristics more often than did parents in the Asperger's syndrome group. Two characteristics – "failure to use or respond to gestures" and "language delay" – were significantly more common in both the autism and PDD-NOS groups, while "unusual interaction with or attachment to objects" was more often cited among the autism and Asperger's syndrome groups. "Not playing with other children" was the only characteristic noticed at comparable rates in the Asperger's syndrome and PDD-NOS groups but at a significantly higher rate among the autism group. Results of these analyses are provided in Table 6.

Table 6. Frequencies (%) of Reported Characteristics Among ASD Diagnoses

Characteristic	*Autism*	*Asperger's*	*PDD-NOS*	*$X^2(2)$*
1. Lack of eye contact	135 (78.9%)	28 (70.0%)	29 (69.0%)	2.707
2. Lack of social smiling	81 (46.6%)	13 (32.5%)	11 (25.6%)	7.644*
3. Failure to attach to caregiver	43 (24.9%)	9 (22.0%)	5 (11.6%)	3.493
4. Slowness in meeting motor milestones	60 (35.1%)	13 (31.0%)	13 (30.2%)	0.520
5. Lack of responsiveness (e.g., to name)	142 (85.0%)	19 (46.3%)	28 (66.7%)	28.895***
6. Failure to use/respond to gestures	128 (75.7%)	16 (40.0%)	29 (69.0%)	19.289***
7. Language delay	161 (95.3%)	20 (47.6%)	40 (95.2%)	71.959***
8. Unusual physical behaviours	110 (63.6%)	27 (67.5%)	22 (51.2%)	2.843
9. Unusual interaction with/attachment to objects	117 (68.0%)	25 (65.8%)	19 (45.2%)	7.666*
10. Lack of imaginative or pretend play	134 (79.3%)	23 (56.1%)	27 (65.9%)	10.461**
11. Not playing with other children	143 (85.1%)	27 (67.5%)	26 (63.4%)	12.844**

**p < .05; **p < .01; ***p < .001*

Discussion

Participants provided rich information regarding the early symptoms they noticed as being different in their children. Overall, the very young ages at which they detected atypical behaviour indicates a time lag between symptom presentation and diagnosis that averaged between 13 months and 4.5 years, depending upon the type of ASD diagnosis – a substantially lengthy wait for parents trying to figure out what may be affecting their children. Parents of children who were specifically diagnosed with autism waited, on average, between 1 and 2 years to receive the diagnosis after they first noticed unusual symptoms. However, this is a considerably shorter time lag than the 34-month delay that parents experienced in Young, Brewer, and Pattison's (2003) report. It could be that the earlier diagnoses received by

children in the current sample reflect a continuation of increased autism awareness; alternatively, there could be cultural differences in how autism is perceived and/or diagnosed between the samples, as ours was comprised of primarily U.S. families and theirs, Australian families. Either way, a delay of even one year still translates into a significant loss of early intervention (Chung, Smith, & Vostanis, 1995).

Our data point to the wide variability in whether the children showed the symptom, both across diagnoses and within diagnoses. Characteristics reported at older average ages tended to be reported at higher frequencies, which is in line with many findings that suggest we are better able to detect differences indicative of autism during a child's second year of life (e.g., Adrien et al., 1993; Young et al., 2003). There was no characteristic reported for 100% of the children, even within a diagnosis. This underscores the fact that disorders in the autism spectrum may not have a set of symptoms that are universal. The rank ordering in Table 7 shows the frequency with which children's parents reported their child's autism-spectrum characteristics. These are shown only for characteristics up to 50%. From this listing we can see that only 4 of the characteristics were reported by at least 50% of the parents in each diagnostic group: lack of eye contact, not playing with other children, unusual physical behaviour, and lack of pretend play. The "top three" have little overlap. The autism and PDD-NOS groups both cited language delay as the most frequently reported behavioural characteristic, but this characteristic does not reach even 50% for the Asperger's group. The autism group shows the highest preponderance of symptoms, followed by PDD-NOS, and finally by Asperger's. For most of these characteristics, however, one-third to one-half or more of the parents did not remember this characteristic in their young children.

These findings of great variability mirror those of Young et al. (2003). Their methodology employed open-ended reports of parents' memories of early characteristics, thus they had a wider variety (a longer list) of characteristics than our closed-ended list. But among their most-frequent reports for children with autism were preference for playing alone (100%), difficulty forming friendships (94.9%), lack of eye contact (88.9%), unusual preoccupations (84%), and delayed language (77.8%). Young et al. aimed to make a distinction between core deficit-linked behaviours and secondary behavioural manifestations of the disorder. In their model, the core behaviours reflect the underlying neurological problems while secondary manifestations reveal an individual's coping with the disorder. While a theoretically attractive idea worthy of further study, these distinctions are not yet clear in either their data or ours.

Table 7. Rank-Orderings of Parent-Reported Frequency of Early Characteristics in Children With Autism, Asperger's, or PDD-NOS

Autism	*f**	*Asperger's*	*f*	*PDD-NOS*	*f*
1. Language delay	92.5%	1. Lack of eye contact	66.7%	1. Language delay	93.0%
2. Not playing with other children	82.2%	2. Unusual physical behaviors (tie)	64.3%	2. Lack of eye contact (tie)	67.4%
3. Lack of responsiveness	81.6%	3. Not playing with other children (tie)	64.3%	3. Failure to use /respond to gestures (tie)	67.4%
4. Lack of eye contact	77.6%	4. Unusual interaction with /attachment to objects	59.5%	4. Lack of pretend play	62.8%
5. Lack of pretend play	77.0%	5. Lack of pretend play	54.8%	5. Not playing with other children	60.5%
6. Failure to use /respond to gestures	73.6%			6. Unusual physical behaviors	51.2%
7. Unusual interaction with /attachment to objects	67.2%				
8. Unusual physical behaviors	63.2%				

**f = frequency*

Our data also point to the wide variability in the ages at which early characteristics were first noted. Our study and Young et al.'s (2003) both asked parents to report the ages at which their children first showed worrisome signs. The set of 33 behaviours listed by the Young et al. (2003) research team is different from the 11 behaviours used in our study, but comparisons can be made for a few of the behaviours. We found remarkable similarity in the mean-age reports for "language delay" (a mean of 1.5 years in Young et al. vs. 1.6 years in our sample), "not playing with other children" (1.85 years in Young et al. vs. 1.9 years in our sample), and "lack of eye contact" (1.75 years in Young et al. vs. 1.5 years in our sample). Other age reports were farther apart: "failure to attach to caregiver" (1.7 years in Young et al. vs. 1.2 years in our sample), "unusual interaction with/attachment to objects" (2.3 years in Young et al. vs. 1.7 years in our sample). What is perhaps most notable in both studies is the wide range of age at which parents first noticed an unusual behaviour, a range that often spanned 3 years or longer. It is clear that we do not yet have a definitive set of age expectations for the appearance of anomalous behaviours in children with ASD.

Overall, our data show that children diagnosed in the autism spectrum showed delayed or anomalous behaviour earlier than the 3 years at which *DSM-IV* diagnoses are usually made. There is variability in which specific behaviours were noticed by parents as well as a wide age range for the appearance of autistic-like characteristics. This range, no doubt, reflects the fact that (a) some children show signs of autism from birth, while others experience a regressive onset after a period of typical development, and (b) the difficulty of remembering when a symptom first came to parents' attention. Beyond these two sources of difficulty, our data from a large sample of families suggest that "variability is the norm," including variability both in whether specific behaviours occur and when they occur.

Limitations

It must be noted upfront that these data are all from parent report and were not confirmed by any additional means. Parents' recollections and impressions are not exact and unchangeable blueprints of what happened. Rather, we are all influenced by what we read, people we meet, and new interpretations of old ideas (Myers & Williams-Petersen, 1991). Thus, reported diagnoses of children and family members may or may not be correct. In the same way, parents' recollection of when they first noticed a developmental or behavioural anomaly is also a retrospective report; they may or may not have actually noticed it at the ages reported, and they may or may not remember what they noticed. Several works, however, attest to

the validity of parents' reports on their children's development and the congruence between parents' and clinicians' observations of children (Ireton & Glascoe, 1995; Schulman, 2001; Siegel et al., 1988; Stone et al., 1994). Therefore it is also possible that these parents painted a fairly accurate picture of their children. The intensiveness of the phenomenon of autistic emergence has been well documented with smaller samples that allowed for concentrated, and sometimes longitudinal, focus on which characteristics defined autism (see previously cited studies). To understand the extensiveness of this phenomenon – the pervasiveness of the identified characteristics of autism, particularly across different ASD diagnoses – we needed a large sample. Our chosen methodology proved fruitful in this sense; however, the ideal approach to the study of autistic emergence would combine the best methods of both intensive and extensive investigations-consistently, objectively, and longitudinally monitoring the development of high risk infants (e.g., the siblings of already diagnosed children) within a very large sample.

An important limitation is that the questionnaire was solely available in electronic format, so only families who had access to computers and the internet were able to learn about and participate in the study. Accordingly, low-income and minority families were definitely underrepresented in our sample. Additionally, families were notified about the study through newsletters and websites of official autism societies, but not all affected families belong to such groups and so did not have the opportunity to hear about the study.

A recent analysis, however, comparing web-based with traditional survey research (e.g., mailed questionnaires, telephone interviews) concluded that many of the concerns specific to web-based research are unfounded (Gosling et al., 2004). Specifically, they found (a) study samples to be comparable with respect to gender, socioeconomic status, geographic region, and age; (b) that findings are not tainted by false data or repeat responders; and (c) that studies' results are not different across formats. This is not to suggest that the process of web-based data collection is identical to all other types of collection strategies; in particular, it differs from in-person and clinical studies in that a researcher is not available to interact with participants and clarify questions they may have about specific questionnaire items. This is especially relevant to the clinical sample in this study, for we were not able to confirm the diagnoses supplied by the parents or the actuality of the (retrospective) symptoms they reported. We did, in fact, review the data carefully to rule out repeat responders (there were none) or potential false responders making up silly answers. There were, again, none of these.

There is a balance to consider. This new methodology makes it possible to connect with select and hard-to-reach samples, which makes it a useful tool for targeting families with autism. At the same time, some potential respondents were missed, and the perspectives of families with different life circumstances may be qualitatively different from those represented in this work. To obtain reports specifically from those populations that escaped inclusion within the current study, it may be necessary to employ a more traditional survey tactic, such as mailing questionnaires, combined with an effort that targets those groups of interest through local contacts (e.g., minority autism-support groups).

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