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Parental Reports of the Development of Autism in Their Children: The Relevance of Regression, Comorbidity, and Genetics in the Detection of Early Characteristics

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Parental Reports of the Development of Autism in Their Children: The Relevance of Regression, Comorbidity, and Genetics in the Detection of Early Characteristics

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

by

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Abstract

PARENTAL REPORTS OF THE DEVELOPMENT OF AUTISM IN THEIR CHILDREN: THE RELEVANCE OF REGRESSION, COMORBIDITY, AND GENETICS IN THE DETECTION OF EARLY CHARACTERISTICS

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy at Virginia Commonwealth University.

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Early detection of autism plays an important role in enhancing developmental outcomes for affected children. Identifying potential characteristics of the disorder evident during infancy and toddlerhood aids efforts to screen for such symptoms, which may lead to earlier and more accurate diagnoses; however, it is unclear to what extent certain factors encourage or impede early detection. Because parents are responsible for making decisions on behalf of their children based upon their perceptions of children's developmental progression, caregivers were queried in terms of their beliefs about the development of autism characteristics in their children. Participants included 393 caregivers of children with autism, Asperger's syndrome, and PDD-NOS from the U.S.

and 5 other English-speaking countries who completed an online questionnaire containing both closed- and open-ended questions. Rich, descriptive information on children was provided in terms of demographic variables, comorbid diagnoses outside of the autism spectrum, the type of autism onset (congenital or regressive) children experienced, the presence of a family history of autism or other mental-health disorders, and the ages at which behavioral difference were detected for 11 early symptoms indicative of autism. Analyses were conducted with the last 4 variables within this list and with an additional variable reflecting parents' beliefs about the etiology of autism (genetic versus some external mechanism). Significant relationships existed between a variety of these variables with the exception of a family history of autism or other mental-health disorders. About half of the sample reported that their children developed autism in a congenital fashion while the remaining half, a regressive fashion. Those indicating a congenital onset reported noticing all 11 early characteristics at younger ages relative to those indicating a regressive onset; however, significant differences between groups existed for only 4 of these 11 early symptoms. Parents who indicated a congenital onset were also more likely to espouse a genetic etiology for autism relative to parents indicating a regressive onset who were more likely to attribute the disorder to some external mechanism. Type of autism onset and presence versus absence of child comorbidity independently predicted the ages at which parents detected anomalies in 7 of the 11 early characteristics. Interpretations of the findings are discussed in detail, followed by suggestions for future directions of research in this area.

Introduction

Autism is commonly noted as one of the most profound disorders of childhood. First described 60 years ago by Leo Kanner (1943), autism is a neurological syndrome that interferes with the development of social interaction and communication in young children. Affected individuals also tend to engage in a limited repertoire of activities or interests, often displaying poor personal-attachment behaviors while clinging to a preferred object (APA, 2000). Social-skill dysfunction is one of the most salient markers of the disorder, as these children fail to establish relationships with others or to engage in joint-attention behaviors (Koenig, Rubin, Klin, & Volkmar, 2000). They also tend to perform stereotyped and repetitive behaviors and may be inflexible to change, preferring apparently nonfunctional routines or patterns. Typically, they present with communication delays, both verbal and nonverbal, and some never develop language at all. Cognitive skills are sometimes impaired, as 75% to 80% of individuals with autism are also diagnosed with mental retardation (APA, 2000). It has been hypothesized that these individuals focus on "dissociated fragments rather than integrated 'wholes,' leading to a fragmentary and overly concrete experience of the world," (Koenig et al., 2000, p. 302) and lack a "theory of mind," or knowledge that individuals are mentally distinct and can have attitudes and beliefs separate from their own (Koenig et al., 2000).

Autism, unlike some other neurological and developmental disabilities, does not have an obvious phenotype. There are, however, factors that place individuals at increased risk for developing the disorder. Autism occurs 4 to 5 times more often in males than in females, and individuals with a family history of autism are more likely to

be affected (APA, 2000). Twin studies reveal a higher concordance rate for autism in monozygotic twins versus dizygotic twins, and monozygotic twins and non-twin siblings of children with autism are significantly more likely to develop autism or mild symptoms of the disorder, relative to the general population (Rutter, Silbert, O'Connor, & Simonoff, 1999b). Developmental skills may not emerge at a typical or expected pace in individuals with autism, so that some children may be on-track or even precocious (relative to their nondisabled peers) in one area but markedly behind in another (APA, 2000). In an interesting examination of the pediatric neurodevelopmental profiles of 168 children diagnosed with autism or PDD-NOS (143 males, 25 females; *M* age = 44.8 months, *SD* = 14.9 months, range = 15 to 117 months), Voigt et al. (2000) noted (a) a statistically significant discrepancy between language and visual-motor problem-solving scores, indicating a delay in language development relative to visual-motor problem-solving development and (b) a trend for those children exhibiting fewer overall cognitive difficulties to have greater discrepancies between their language and visual-motor problem-solving scores relative to children with more severe cognitive impairments.

Incidence of Autism

Estimates of the incidence of autism vary widely and have been reported to be on the rise in recent years. In 1994, the *DSM-IV* indicated that the incidence of autism was between 2 and 5 individuals per 10,000 (APA, 1994). A report in 2000, however, suggested that the disorder currently affects about 20 children per 10,000 (Filipek et al., 2000), and using ICD-10 criteria, estimates have ranged up to 30.8 per 10,000 (Burd, Fisher, & Kerbeshian, 1987; Baird et al., 2000). Thus it appears that the number of

diagnosed cases has increased during an 8-year span of time. Researchers around the world have conducted epidemiological investigations to document potential increases in autistic incidences. Fombonne, DuMazaubrun, Cans, and Grandjean (1997) found rates of 5.4 (classic autism) and 16.3 (other autism-spectrum disorders) per 10,000 in their epidemiological survey among 325, 347 French children, and Powell et al. (2000) uncovered rates of 3.5 (classic autism) and 4.8 (other autism-spectrum disorders) per 10,000 among 178, 484 rural British preschoolers. Croen, Grether, Hoogstrate, and Selvin (2002) noted a rate of 11 (for autism) per 10,000 in California, while Madsen et al. (2002) found incidence rates among Danish 8-year-olds with autism and other autism-spectrum disorders at 7.7 and 22.2 per 10,000, respectively. In their meta-analyses on the incidence of autism, Wing (1993), Gillberg and Wing (1999), and Wing and Potter (2002) reported global increases of the disorder. Derived from an analysis of 16 epidemiological studies of autism in various countries, incidences of autism ranged from 3.3 to 16 cases per 10,000 in 1993 (Wing, 1993). In a second report 6 years later that included 20 international studies, Gillberg and Wing (1999) found that incidences ranged from 3.3 to 31 cases per 10,000, with notable increases in the number of autism cases in studies that only included children born after 1970. Three years later, Wing and Potter (2002) published a third review of this literature, which considered 39 autism-prevalence studies from around the globe, the highest of which reported a prevalence rate of 60 autism cases per 10,000.

Croen, Grether, Hoogstrate, and Selvin's (2002) report, as well as Yeargin-Allsop et al.'s (2003) study that noted an increased prevalence of 3.4 cases per 1000 in

metropolitan Atlanta, have recently incited curiosity as to the reason for the rising incidence of autism and autism-spectrum disorders. Suggestions include improved diagnostic capabilities, expanded criteria inclusive of milder cases of autism (such as Asperger's syndrome), related decreases in other diagnoses, such as mental retardation (Croen, Grether, Hoogstrate, & Selvin, 2002), increased awareness of autism-spectrum disorders, and use of differing diagnostic criteria (e.g., DSM-IV versus ICD-10) (Wing, 1993; Wing & Potter, 2002). Some link the increase in autism-spectrum disorders to the mumps, measles, and rubella (MMR) vaccination, citing mercury within the inoculation as the culprit. The fact that incidences of both autism and MMR-vaccination rates have increased over time and autistic symptoms, particularly regressive symptoms (e.g., loss of language or motor skills), are commonly reported by parents following their children's immunizations render the vaccine a potential cause (DeStefano & Chen, 2001). However, epidemiological and registry-based reports have failed to establish a significant relationship between the MMR vaccine and autism (DeStefano & Chen, 2001; Fombonne & Chakrabarti, 2001; Madsen et al., 2002; Taylor et al., 2002). Certain pesticides and related poisons ("New Center to Study," 2001) and food allergies (Renzoni et al., 1995), particularly allergies to wheat and dairy products (Dantini, 2002), have also been implicated as potential environmental triggers of autism. Many parents (as well as some professionals) are convinced that one or more of these environmental agents triggered autism in their children. At this point, however, such claims for external causes of autism lack empirical support, and more research is warranted to validate their relationships to the disorder.

Cultural and Family Influences on Autism

With respect to race and other demographic variables, it has been stated that, "Autism…knows no racial, ethnic, or social boundaries. Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence," (Autism Society of America, 2000, p. 3). Yet race, ethnicity, and corresponding cultural variables have typically escaped rigorous consideration in the autism literature (Connors & Donnellan, 1998). Croen, Grether, Hoogstrate, and Selvin (2002) noted that increases in the incidence of autism in California were not related to child gender, race, birth plurality, maternal age, or maternal education, and in their work on the relationship between autism and the MMR vaccine, Madsen et al. (2002) noted that gender, calendar period, socioeconomic status, maternal education, and child's gestational age and birth weight did not confound risk estimates.

Earlier view that autism differed across racial and economic groups. These recent accounts attest to the fact that autism occurs across racial and economic groups. They stand in contrast to past beliefs that autism was largely a European and European-American disorder. In a review of this literature on this topic during the early 1980's, Sanua (1981) claimed that autism prevails in Anglo cultures, with seemingly few reports of autism cases arising within Hispanic/Latino, African, and Chinese populations.

During the 1960's and 1970's, several researchers examined the assumed disparate prevalence of autism in Anglo versus non-Anglo groups from a sociological perspective, citing potential cultural differences in the socialization of infants and family networks as contributing to the disorder. In his review of this literature, Sanua (1981)

asserted that Western societies and industrialized nations (specifically, the United States, England, Canada, Australia, and Japan) have greater numbers of children with psychiatric illnesses. He further proposed that modern family trends and the changing roles of women in these countries contributed to the rise of autistic incidence, further claiming that because women have fewer children and often work outside the home, women were spending a smaller part of their lives devoted to raising children: "Since the child is so much influenced by the family structure, changes within that structure are bound to have an enormous impact on his socialization and mental health," (Sanua, 1981, p. 134). Sanua backed up his thesis with cross-cultural evidence of differences both in the incidence of autism and the prevalence of mothers who were employed. For example, a higher proportion of immigrant-Greek children versus immigrant-Italian and Yugoslav children were identified with autism in Harper and William's (1976) Australian study, and the authors attributed the discrepancy to the fact that approximately 70% of Greek mothers worked outside of the home compared with only 30% of mothers in the mainstream population.

Sanua (1981) went on to describe practices in developing countries where the incidence of autism is scant or nonexistent. Women in many African nations maintain close and consistent physical contact with their infants, and they are not left to sleep alone nor left to cry, which contrasts with practices in modern, developed societies where mother and infant are often separated. Moreover, cultures that value family connectedness and support (familism), such as Hispanic/Latino peoples, report fewer incidences of autism (Sanua, 1981), likely because the development of mental

disturbances is seen as mitigated through both intense social connectedness and extended family members assuming any burden affiliated with disability stress.

Current thinking about the causes of autism would disavow, however, Sanua's suggestion that family structure could have an influence on this particular disability. People in the 1960's and 1970's frequently blamed autism in children on the mother, giving her labels such as "refrigerator mom," suggesting that it was her coldness that resulted in a child who was detached from other people. This thinking is soundly rejected today. It underscores, though, the importance of considering people's personal theories of causality about a disability or, more generally, about why children turn out the way they do.

Cultural and economic concerns that remain relevant. With regard to parent intelligence and socioeconomic status, Ritvo et al. (1971) proposed that results from earlier studies, which revealed a disproportionate number of children with autism arising from families of above-average intelligence and higher social classes, were more likely related to methodological flaws of patient selection and the types of patient populations from which their samples were selected, as their own work did not reveal a connection between autism and social class. Subsequent investigation in this arena produced similar conclusions (e.g., Schopler, Andrews, & Strupp, 1979; Tsai, Stewart, Faust, & Shook, 1982). Concerns remain, however, about whether there are cultural, racial, or economic differences in autism. Minority groups are speaking out about the prevalence of autism within their communities, as the *Richmond Times-Dispatch* recently featured an African-American mother organizing other minority mothers who also had children diagnosed

with autism with the intention to offer support and autism awareness to under-served populations (Johnson, 2003).This mother felt that lower-income and minority families received fewer services and less attention than more affluent families. In today's private schools for children with autism, where tuition can be higher than $50,000 per year, the students tend to come from families in the higher socioeconomic brackets. Public school systems typically cannot pay for the expensive one-to-one teacher to child ratio that such schools employ. The previous stereotype was that autism was indeed a disease of the rich and affluent, as these were the families who signed up for expensive treatments and took part in research. It is more likely that these parents have, and had, both the know-how and the wherewithal to access the best services for their children. Because they could financially afford the services, they were found and included in research studies.

A review of Medicaid specialty clinic files in Philadelphia of children receiving services for autism in 1999 found that black children required more time in treatment before receiving an autism-spectrum diagnosis, with white children diagnosed on average at 6.3 years and black children at 7.9 years (Mandell, Listerud, Levy, & Pinto-Martin, 2002). It was apparent that part of this discrepancy could be attributed to the age at which children first appeared for treatment. White children entered the mental-health system at an earlier age (6.0 years) than did black children (7.1 years). That delay in help-seeking may result from parents themselves not seeking help, previous pediatricians not noticing signs of difficulty, or from systemic clinical behaviors disfavoring the black children. Thus, while disparities existed in how long it took for minority children to be diagnosed, the precise causes for this difference needed more study.

Parents' Construction of Beliefs About Their Children

The question underlying parents' perception of the development of autism in their children is the larger question of the construction of all parents' belief systems about their children. Whether they are termed beliefs, thoughts, constructs, theories, ideas, goals, or perceptions, all adults have cognitions about children (Sigel, McGillucddy-DeLisi, & Goodnow, 1992). This inquiry is grounded in a constructivist theory of communication that suggests meaning is constructed and not inherent or objective or given. Scientists in this field share a central conviction that parental cognitions *do* matter, in ways that are both direct and indirect (Sigel, et al.). They matter in how children are raised and in children's own experiences of life.

Parents and families follow codes that organize individuals within the family system (Sameroff & Fiese, 1992). These codes serve as guidelines for testing what is true and not true and for guiding parental behavior. The codes are not talked about, and members are mostly unaware of them. An example is the family paradigm, or idea about the social world, and includes beliefs such as how information is to be shared within and outside the family. Family myths are part of the code. They sometimes regulate role definitions—mother can handle the checkbook but not the investment accounts; the child with a disability is to be treated as the youngest child, even though he is the oldest of five children. Family members are typically unaware of these codes but at the same time believe in them unquestionably.

Parents' goals can be specific and conscious, as well. They include expectations for their children's behavior—that children should do their homework before they play,

for example, or that everyone should come to the table promptly when called for dinner. The families' goals guide their socialization practices with the children, thus guiding whether the family budget shall be spent first on the mortgage, ballet shoes, piano lessons, or video games. Some beliefs vary across cultures. For example, American parents stress active interaction with their babies and toddlers to get the children ready to learn in school (and tend to let teachers take charge of learning once the child enters first grade), while Japanese parents increase their parenting efforts as they guide children in their school years (Sameroff & Fiese, 1992).

One factor warranting attention in this arena is how families within a given culture appraise their situations with children experiencing autism and that members of various cultural groups may evaluate this experience differently, some viewing it positively and others negatively (Dyches, Wilder, & Obiakor, 2001). Groups that do not necessarily view such disturbances or differences in people as negative and, instead, assimilate individuals with disabilities into mainstream society, such as the Native Hawaiian and Navajo cultures, logically do not seek professional services to understand or mitigate autism characteristics. In a similar vein, McClure (1992) noted that many disorders recognized in Western cultures are not necessarily viewed as psychiatric illness in China. On the other hand, cultural stigmas of disability may lead members of some cultural groups to avoid services that would label, and thereby negatively sanction, their children. As Dyches, Wilder, and Obiakor (2001) stated:

> "…some South Asian families may not refer their children for services, especially if their child is a girl, for fear that they may not be able to arrange a marriage.

> Fear of stigma has also been reported in African American families…(who) tend to access services provided by professional organizations less frequently than the majority culture and only after relying on family, friends, religion, and church support," (p. 163).

Whether autism and other disabilities/differences are viewed positively or negatively within certain populations, these examples illustrate how incidences of autism may go underreported based on different cultural perceptions of disability and therefore seem absent among some ethnic groups.

In the current study, we are asking parents for their memories of when they first noticed that their children showed delays or atypical behavior. Are their memories an accurate reflection of an objective truth about when their child first showed delays or regressions? A study of mothers' and grandmothers' memories about child-rearing across generations provides some clues that "memories" are not objective recordings but constructions that are consistent with a person's current thinking (Myers & Williams-Petersen, 1991). Grandmothers and mothers of 1-year old infants rated the frequency of 14 child-rearing techniques or values (such as spanking and permitting treats), both for when the mothers were little girls (and the grandmothers were raising their children) and for today, reporting on how they treat the child/grandchild now. Grandmothers and mothers most often had *different* memories of the past, yet believed that they were behaving *today* much as happened in the past. The findings were interpreted with the view that memory of the past is not an exact copy of the past but rather is a reconstruction that is transformed by new understandings and contemporary events. Both the mothers

and the grandmothers created a story that was consistent within themselves. It is likely that, in this current study, parents who report on their children's past behavior will also be creating a construction, a consistent picture. This view does not in any way devalue or discredit that construction, for it is only in constructing a consistent point of view that we can create meaning in the string of events that happen in life. This sense-making is the serious endeavor that thinking people create, and it is the focus of this study.

Review of the Literature

Value of Early Detection and Diagnosis

For a clinical diagnosis of autism, characteristics must present prior to 3 years of age; however, in some cases, a period of apparently normal development may precede atypical functioning. Usually, children are not diagnosed with autism until age 3 or later, likely because it is difficult to distinguish between autism and other childhood disorders, such as developmental delays and mental retardation. In addition, there appears to be a "relative lack of available professional expertise and provision [of services]," for this population (Smith, Chung, & Vostanis, 1994, p. 552). However, because many parents of children who were later diagnosed with autism reported concerns about their children's atypical development during infancy, researchers have begun to explore the possibility and validity of detection prior to age 3.

The importance of early detection of autism is twofold. One is that children who are accurately diagnosed will have immediate access to intervention services. Because *DSM-IV* diagnoses oftentimes are not made until 3 years of age or later, affected infants and toddlers are missing out on immediate therapeutic options. According to Rogers (1998), children with autism who are treated early exhibit significant improvements in functioning relative to older children with autism undergoing the same interventions. Thus, early detection of autism that leads to early intervention seems key to improving developmental outcomes for these children.

Secondly, being the parent of a child with a disability can be frustrating, particularly if parents suspect something is "wrong" but cannot find any help or answers.

It is difficult to care for and connect with a child who lacks eye contact, ignores socialization attempts, and does not communicate. Additionally, some parents have relayed frustration in trying to get a diagnosis and services from professionals, asserting that specialists dismiss their opinions and concerns about their children (Schall, 2000). Unfortunately, doctors are not always the most adept at identifying early characteristics of autism, as Bonner and Finney (1996) stated that, "Evidence of psychopathology…is frequently ignored or misdiagnosed by primary care physicians and has therefore been referred to as the 'new hidden morbidity,'" (p. 237). In his qualitative analysis of parents' explanatory models of autism, Gray (1995) discovered that:

> "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).

As Goddard, Lehr, and Lapadat (2000) stated, "They [parents] described a system that compartmentalized, that regularized, and that fostered fear, confusion, and frustration. Within this overriding system, problems of coping with disability emerged," (p. 283). Parents need accurate information on their children's difficulties so that they can learn how to best care for and manage them, as well as relationships with a sensitive and knowledgeable team of providers who responds to their concerns. Earlier detection may mitigate long-term familial stress over the uncertainty of what is affecting their children. With a diagnosis, parents can become educated about autistic disorders, make informed

decisions on best-care practices for their children, and move in an appropriately therapeutic direction.

Given the importance of early detection, then, it is necessary to examine those characteristics in populations younger than age 3 that initially caused parents to believe that something was different about their children. Current diagnostic criteria, according to the *DSM-IV-TR*, describe behaviors (either present or absent) that are appropriate to consider in preschool-aged and older children; however, it is not always appropriate to compare infants and toddlers against this same criteria simply because they have not yet reached developmental levels at which they can be expected to perform (or not perform) given behaviors. It is probable that symptoms of autism present in very young children in qualitatively different ways relative to how it presents in children aged 3 and older. Moreover, it is likely that other factors impact the detectability of these early signs, either masking them, which make accurate diagnoses more difficult, or exacerbating them. Three logical factors to consider as potentially impacting early-autism detectability are developmental regression, cormorbid diagnoses, and genetics, or a family-history of mental-health disorders. However, it is unknown how these variables influence, either individually or in conjunction with one another, the identification of early symptoms.

Research on Autism-Spectrum Traits in Infancy and Toddlerhood

At their meeting in 1998, the National Institutes of Health Autism Coordinating Committee explored the status of research in the field of autism and outlined areas of highest priority for continued research efforts. While the search for a causal mechanism topped the list, improvements in diagnostic capabilities, particularly with infants and

toddlers, came in at a close second (Bristol-Power & Spinella, 1999). In support of this focus on autism as detected during infancy, the National Institute of Mental Health (NIMH) advertises a list of behavioral differences indicative of infants at risk for developing autism, which can be seen in Table 1. The behavioral cues suggestive of autism are contrasted, point for point, with the behaviors of typical infants.

Table 1

Difference in the Behaviors of Infants With and Without Autism[1]

Infants with Autism	Normal Infants
Communication	
• Avoid eye contact	• Study mother's face
• Seem deaf	• Easily stimulated by sounds
• Start developing language, then abruptly stop talking altogether	• Keep adding to vocabulary and expanding grammatical usage
Social relationships	
• Acts as if unaware of the coming and going of others	• Cry when mother leaves the room and are anxious with strangers
• Physically attack and injure others without provocation	• Get upset when hungry or frustrated
• Inaccessible, as if in a shell	• Recognize familiar faces and smile
Exploration of environment	
• Remain fixated on a single item or activity	• Move from one engrossing object or activity to another
• Practice strange actions like rocking or	• Use body purposefully to reach

[1] Take from pp. 3-4 of the NIMH website on autism, (NIMH, 1997).

hand-flapping • Sniff or lick toys • Show no sensitivity to burns or bruises, and engage in self-mutilation, such as eye gouging	or acquire objects • Explore and play with toys • Seek pleasure and avoid pain

On his website providing an overview of autism, Edelson (1999) stated that, "Many infants with autism are different from birth," (p. 1). They commonly evade physical contact by arching their backs away from caregivers and fail to anticipate being picked up (i.e., do not lift their arms). They may be described as difficult babies, repetitively rocking or banging their heads against the crib, or as quiet, passive infants. On the other hand, he notes that some infants later diagnosed with autism seem to develop normally during the first 2 years but then lose certain skills and social behaviors (e.g., talking). In their chapter discussing problems associated with autistic diagnoses among infants, Young and Brewer (2002) stated that:

> "Although many features of Autistic Disorder are present in the first year of life, we remain unable to diagnose autism accurately in children less than two years of age. This failure is not due to the lack of symptomatology, but rather to the inability of researchers and clinicians to identify the specific behaviors characteristic of autism in very young children. We know that children under two can be identified by trained clinicians, yet the behaviors that are critical for this diagnosis have not been consistently recognized. While failure to respond to one's name or unusual eye gaze are often cited as significant to the onset of autism, the role that these behaviors and others play in its development are not understood," (p.108)

Clearly, such characteristics are important to document across samples in order to enhance early diagnostic capabilities, and two different lines of research do just that: observations of family home videos and use of early screening devices.

Family home videos. As a means of identifying potential early characteristics of autism, several researchers have adopted a retrospective approach by examining family-home videos of children who were later diagnosed with autism. Such videotapes are particularly useful for this type of exploration because they yield consistent and objective data that are not influenced by parents' potentially inaccurate recollections. Based on pilot work, Adrien et al. (1993) hypothesized that (a) abnormal behaviors indicative of infantile autism would be noted (via home videos) prior to age 2 in most cases and (b) that those with autism would be distinguishable from typically developing children prior to a clinical diagnosis. Participants included 12 children who were all older than 2 years of age and who had been diagnosed with infantile autism according to *DSM-III-R* criteria, contrasted with 12 typically developing children of the same age. Home videos for each group were coded using the Infant Behavior Summarized Evaluation scale (IBSE) (Barthelemy et al., 1990) by 2 diagnosis-blind raters, and ratings were categorized into first year (0 to 1 year of age) and second year (1 to 2 years of age) for comparative purposes. Their results showed that 5 out of 19 specific behaviors significantly differentiated children with autism from typically developing children during the first year of life: poor social interaction, no social smile, lack of appropriate facial expressions, hypotonia, and unstable attention (easily distracted). During the second year of life, differences between the two groups remained, as symptomatology was more intense and shown by the following behaviors: ignores people, prefers aloneness, no eye contact, lack of appropriate gestures and/or expressive postures, too calm, unusual postures, hypoactivity, and no expression of emotions.

Researchers employing the IBSE have used family-home movies to both identify early characteristics of autism in very young infants and differentiate autism from Rett's syndrome, a closely related disorder that shares many of the same characteristics but only affects females. Carmagnat-Dubois et al. (1997) coded videotapes of three groups of children: Rett's syndrome (n = 9), autism (n = 9), and typical (n = 9) using a 33-variable scale that rated areas such as ignores others, prefers to be alone, absence of vocalization, and lack of smiling (IBSE; Adrien et al., 1993). Family videos of the children taken during the first 2 years of life were coded by raters blind to later diagnoses. Neither autism nor Rett's syndrome could be differentiated from typically developing infants in videos of the first 6 months. Children with Rett's syndrome and those with autism were both distinguishable from typical infants aged 6-12 months and 12-18 months. Children with Rett's syndrome had lower cognition scores relative to those with autism at 12-18 months, but otherwise the Rett's and autism groups were not different.

Zakian, Malvy, Desombre, Roux, and Lenoir (2000), another research team detecting autistic characteristics in a young group, compared videotapes of 14 infants later diagnosed with autism with those of 10 typically developing infants in time brackets of 0-8 months of age, 9-17 months, and 18-24 months. Blind raters using the IBSE described infants with autism as more docile, not seeking contact, and failing to produce pre-language sounds. A few such differences were perceptible during the first few months of life, though they became more pronounced in the later periods.

Werner, Dawson, Osterling, and Dinno (2000) compared videotapes of 15 infants subsequently diagnosed with autism with a control group of 15 typically developing

infants. Tapes of infants aged 8 to 10 months were coded by diagnosis-blind raters for instances of social behaviors (e.g., looking at others, looking at a face and smiling, and orienting to name), communicative behaviors (e.g., simple vowel sounds, consonant-vowel combinations), and repetitive behaviors (e.g., appropriate versus inappropriate). Children experiencing autism were significantly less responsive to their names, and a marginally significant finding revealed that they were less likely to be looking at another individual when they smiled. However, it should be noted that the two groups did not differ on most of the coded behaviors.

Other researchers have used videotape records to examine gross-motor characteristics of children later diagnosed with autism. Teitelbaum, Teitelbaum, Nye, Fryman, and Maurer (1998) compared body movements in videotapes of 17 infants who were diagnosed with autism after age 3 with those of 15 typically developing infants. Using Eshkol-Wachman Movement Notation (Eshkol & Wachman, 1958), he analyzed the physical actions of infants lying (both on the back and stomach), rolling over, sitting, crawling, standing, and walking. Infants later diagnosed with autism expressed significantly more atypical movements during the processes of rolling over, sitting up, crawling, and walking. These actions were described as awkward and without symmetry. Movements were poorly coordinated, lacked organized timing with each other, and often resulted in toppling over or falling down. Additionally, the author noted that many of the disturbed movements were located on the right side of the body, which differs from yet mirrors reports of similar disturbances expressed by children later diagnosed with schizophrenia who had left-side difficulties.

Baranek (1999) examined videotapes of 32 children between the ages of 9 and 12 months for sensory-motor variables that would discriminate those with autism from both children with general developmental delays and typically developing infants. Raters blind to the purpose of the study coded videotapes of children subsequently diagnosed with autism (n = 11), children with developmental delays (n = 10), and typical children (n = 11) for frequencies of 12 categorical behaviors (e.g., affective expressions, looking, response to name), including 4 behaviors of sensory modulation (tactile, auditory, visual, and vestibular). The author noted that while the developmentally delayed group exhibited significantly more stereotyped play and less looks toward the camera person relative to the autism and typical groups, both the autism and developmentally delayed groups illustrated more atypical postures compared with the typical group. Additionally, infants in the autism group were significantly less likely to respond to their names compared with infants in the other two groups. Marginally significant differences for the autism group included less orientation to visual stimuli, more instances of mouthing objects, and more aversions to social touch. Subsequent discriminative analysis revealed that 9 of the original 12 categorical behaviors correctly predicted group membership in 93.75% of the cases, with the variables of mouthing, social-touch aversions, orienting to visual stimuli, and number of name prompts distinguishing children with autism from those in the other two groups.

Clearly, videotape examination is a useful tool for observing behaviors of children with autism during their infancy and toddlerhood, prior to their diagnoses. It is an objective method that offers repetitive viewing for more accurate scrutinizing of specific

incidences, unlike real-time observations and parent recollections. Although sample sizes for videotape analysis tend to be small (because of the difficulty in locating families with a child experiencing autism who have videotapes of their children at specific ages and who are willing to participate), the aforementioned studies indicate that it has become a popular and promising technique for discovering such pre-diagnosis behavioral differences.

Early screening devices. Autism-spectrum disorder screening instruments for use with infants and toddlers could become an efficient and cost-effective tool for earlier diagnoses. In fact, so important is this mission that the American Academy of Neurology and the Child Neurology Society recently issued a statement regarding the urgency of better screening and diagnostic devices and processes for families of children with autism. Their proposal strongly advocated mass screening of all children for atypical development, especially those at-risk for developing autism (Filipek et al., 2000). The conventional diagnostic age of autism is approximately 3 years, but screening instruments, if effective, could play a crucial role in earlier identification of children who may express autistic-like symptoms, need continued developmental monitoring, and might benefit from immediate intervention services. They are a first step, to be followed by more careful analysis and diagnosis.

An ideal screening device is both sensitive and specific. A test that is sensitive correctly captures or identifies a high percentage of individuals who truly have the condition; it allows very few to slip through and be misidentified as not having the condition (i.e., false negatives). However, specificity must balance the wide net of

sensitivity. A screen that is overly liberal in identifying individuals with a condition falsely categorizes some as having the condition when, in reality, they are free of the condition (i.e., false positives). Specificity refers to lowering the number of or eliminating these falsely identified individuals and trying, instead, to identify only the ones who truly have the condition. There is always a tension between sensitivity and specificity. Here, we want a device that identifies all the children who have autism but that rules out every child that does not.

In just the opposite fashion of retrospective researchers, investigators examining the validity and reliability of screening instruments take a prospective approach in predicting which infants and toddlers are likely to develop autism, based on present characteristics. In their review of screening devices and diagnostic instruments for autism, Gillberg, Nordin, and Ehlers (1996) noted that adequate screening tools for use with infants and toddlers include the Symptoms of Autism Before Age 2 Checklist (SAB-2) (Dahlgren & Gillberg, 1989), the Infant Behavioral Summarized Evaluation Scale (IBSE) (Barthelemy et al., 1990), and the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen, Allen, & Gillberg, 1992). Other screening instruments for children birth to age 3 currently undergoing assessment include the Pervasive Developmental Disorders Screening Test-II (PDDST-II) (Siegel, 2001) and the Modified Checklist for Autism in Toddlers (M-CHAT) (Robins, Fein, Barton, & Green, 2001). Additionally, Stone, Coonrod, and Ousley (2000) have worked with young children to develop and validate the Screening Tool for Autism in Two-Year-Olds (STAT) (Stone & Ousley, 1997), a second-stage screening instrument specifically designed to distinguish toddlers with

autism from those with other developmental disorders. These screening devices are primarily based on observations and simple testing (e.g., calling the child's name to see if he/she responds), although some include a parent-questionnaire component. They are distinguished from strictly interview and questionnaire screenings that are used with parents to ascertain general developmental status and are more specifically geared toward autism-related characteristics. The most widely researched of these screening instruments appears to be the CHAT, a 14-item assessment tool incorporating both parent reports and observations.

Baron-Cohen, Allen, and Gillberg (1992) compared a typically developing group of 18-month-olds (n = 41) to a group of 19-month-olds (n = 50) considered at high risk for developing autism because of an older sibling's diagnosis with the disorder. Both groups were administered the CHAT, and follow-up data regarding children's diagnostic status was obtained 1 year later. While CHAT scores of the at-risk group did not differ significantly from those of the typical group, the former had fewer displays of protodeclarative pointing, social interest, joint attention, and pretend play. Social play was noted in all participants with the exception of four children in the high-risk group who lacked at least 2 of the 5 key social behaviors. At the 30-month-old follow-up, these 4 were the only ones who had been diagnosed with autism.

Using the CHAT in an epidemiological screening of autism with 16,000 infants in the southeast of England, Baron-Cohen's team of researchers has conducted several studies assessing the validity and discriminative capacities of the instrument. In one investigation, CHAT scores and additional measures, including the Autism Diagnostic

Interview-Revised (ADI-R) (Lord, Rutter, & LeCouteur, 1994) for parents, used to confirm CHAT categorizations, were employed to group children (*M* age = 18.7 months) as autistic (*n* = 12, 2 of whom were later diagnosed with only developmental delay) or developmentally delayed (*n* = 22, 7 of whom were later diagnosed as normal). The remainder of the population, approximately 99.6%, was classified as typically developing. The authors' hypothesis that between 6 and 16 of the 16,000 children would present with autistic symptoms was supported. Follow-up data at 3.5 years on the 10 children diagnosed with autism revealed that, based on additional ADI-R data and professional opinion, all had received an accurate diagnosis (Baron-Cohen et al., 1996).

In another investigation using this epidemiological sample, Charman, Swettenham, Baron-Cohen, Cox, Baird, and Drew (1997) compared samples of male children categorized per the CHAT as typical (*n* = 19; *M* age = 20.3 months), autistic (*n* = 10; *M* age = 20.7 months), and developmentally delayed (*n* = 9; *M* age = 21.1 months) engaging in a series of tasks measuring empathetic response, spontaneous play, structured play, joint attention, and imitation. During each task, the experimenter, the child's caregiver(s), or a combination of the two participated with an individual child to scaffold or attempt elicitation of target behaviors. All task performances were videotaped and later coded by diagnosis-blind raters. The autism group, as compared with both the developmentally delayed and normal groups, showed significantly (a) less empathetic response, (b) fewer bouts of structured play, and (c) less imitation. In terms of joint attention behaviors, the autism group differed significantly only from the typical group, and there were no differences between groups on the spontaneous play task. This same

research team later compared three groups of toddlers—autism group, pervasive-developmental-delay group, and developmental-delay group—on the 5 CHAT tasks: empathetic response, spontaneous play, joint attention, goal detection, and imitation (the absence of the structured play task and addition of the goal detection task were the only observational variations). Significant differences noted for the autism group concerned failure to use social gaze during the joint attention task, poor empathetic response, lack of imitative behaviors, and absence of pretend play, findings with implications for a differential diagnosis of autism at early ages (Charman, Swettenham, Baron-Cohen, Cox, Baird, & Drew, 1998).

All of these results support the CHAT as a reliable instrument of autism detection in a young population and attest to its discriminative properties, relative to other developmental delays. Preliminary findings from investigations with other screening devices (e.g., M-CHAT, PDDST-II) indicate promise for additional, accurate screening tools, some of which are designed for more specific filtering (e.g., STAT). Continued research in this arena that yields consistent and congruent results may foster physicians' regular use of screening tools with young populations at risk for developing autism, or perhaps the mandation of such. Larger-scale screenings, particularly among pediatricians who are more likely to have regular visits with infants and toddlers, mean the potential identification of autistic-like characteristics at both earlier ages and among children whose behaviors elude physicians unknowledgeable about specific autistic symptoms. Following a positive-result screening, these children can be more closely monitored for

developmental differences, families may receive accurate diagnoses earlier, and therapeutic interventions can be implemented sooner.

Parent Reports

While important data can be obtained by directly observing infant and toddler behaviors, parents can also supply answers regarding the development of their children diagnosed with autism. As Rubin and Mills (1992) pointed out, "Parents know their children and how they think about and interact with them better than anyone else," (p. 41). Thus, they are logically in the best position to provide historical information concerning developmental delays, skill regression, patterns of behavior, and behavioral difficulties. Parent-based information is a key component of screening for autism, though parent reports should not be the only component. Parents and other family caregivers are the most intimate observers of their own children, but that intimacy could sometimes blur their objectivity. Additionally, parents not exposed to many other children may not be able to differentiate subtle abnormalities from typical behavior. However, in their work on the process of diagnosing autism, Siegel, Pliner, Eschler, and Elliott (1988) found that parents in their sample made accurate and consistent observations regarding their children's developmental delays at an average age of 18 months. Additionally, Ireton and Glascoe (1995) found that parent reports via the Child Development Inventory (Ireton, 1992), a 270-item questionnaire assessing various domains of development, were highly accurate (as correlated with age), even for children who exhibited developmental delays. In another study examining the agreement between parental reports and clinical observations, Stone, Hoffman, Lewis, and Ousley (1994) discovered that individuals in

both groups noted the same 9 out of 16 behavioral characteristics. Those criteria in which there tended not to be agreement primarily concerned areas of social skills that were more evident in the home environment (e.g., absence of peer interactions), and the authors concluded that both parent and clinician reports bring useful, albeit sometimes different, information to the diagnostic table. In a more recent investigation, researchers examined the agreement between parents' reports of the behaviors of their children with autism and clinicians' evaluations of these children. Findings illustrated an overall 65% agreement between parents and clinicians (considered high), with greater agreement on language skills for children with mild autism and diagnostic criteria for children with profound autism (Shulman, 2001). Such results foster confidence in the validity of parents' perceptions, and many screening and diagnostic instruments now include a parent-report component.

In researching children's developmental histories of autism, one of the most common and important pieces of information to glean is at what age parents became suspicious of potential differences in their child. For some parents, these differences were seen as continuous, while other parents reported typical development at first followed by regression in skills. Smith, Chung, and Vostanis (1994) noted that parents ($N = 127$) of young children (M age = 6.1 years) and parents of older children (M age = 14.2 years) who were diagnosed with autism reported noticing differences in their children at a mean age of 16.8 months ($SD = 13.1$ months) and 17.6 months ($SD = 9.5$ months), respectively. De Giacomo and Fombonne (1998) found that parents ($N = 82$) in their sample reported first concerns when their children were an average of 19.1 months ($SD = 9.4$ months) and

that 80% of these parents recognized developmental differences by their children's second birthdays. In Williams and Ozonoff's (2001) work, autistic regression was noted (after a period of normal development) at an average age of 16.6 months. Young, Brewer, and Pattison (in press) revealed that 28 (34.6%) parents in their sample described their children as exhibiting congenital autism while 48 (59.3%) parents believed their children experienced a period of typical development prior to autistic onset. Among the latter group, regression was noted at a modal age of 18 months (range = 5 to 36 months). Additionally, some researchers choose only to focus on the 12 to 18-month age range for gathering information on parents' early developmental concerns (e.g., Vostanis et al., 1998). All of these findings lend credence to the notion that autistic-like symptoms present well before age 2, much earlier than current diagnostic capabilities can confirm, and that parents are attuned to such differences.

In their work on the detection and rating of early parental concerns, Vostanis et al. (1998) compared reports from parents of children (N = 121; M age = 5.1 years) with autism, learning disabilities, and other disabilities not categorized as PDD or learning disorders. Using their own developmental screening questionnaire (included within their report) to retrospectively assess parents' concerns about their children's development between 12 and 18 months of age, they found that parents of children with autism reported significantly lower performances, relative to the other two groups, on most scale items, including "copying adults' sounds, pointing at things, copying others, playing with something unusual, playing peep-bo [peek-a-boo], coming for a cuddle, liking cuddles, checking for [presence of] parents, being interested in animals, being interested in

children of the same age, going to parents for comfort, and waving good-bye without being told," (Vostanis et al., 1998, p. 233). Subsequent regression analyses revealed 4 items that were significantly associated with an autistic diagnosis: playing with the same object, playing with an unusual object, failure to point, and being suspected deaf. In a similar vein, De Giacomo and Fombonne (1998) gathered parents' perceptions of the development of their children presenting with autism and PDD using the Autism Diagnostic Interview-Revised (ADI-R). The most frequently reported concerns were speech/language development, atypical social-emotional responses, and medical difficulties or a delay in reaching a developmental milestone.

Wimpory, Hobson, Williams, and Nash (2000) used their Detection of Autism by Infant Sociability Interview (DAISI) with 10 parents of children with autism and 10 parents of children with non-autism developmental delays to examine the discriminative abilities of the instrument. The DAISI is a 19-item, intensive interview used to elicit parents' recollections about their children's development during their first 2 years of life, and items are scored based on presence or absence of a given behavior. Reports from the parents in the two groups differed significantly, with the children with autism commonly lacking/failing to engage in the following social behaviors: raising the arms to be picked up, eye contact, verbal turn-taking/use of communicative noises, referential use of eye contact, offering/giving objects to others, and pointing/following others' points. In related work, Coonrod, Turner, Pozdol, and Stone (2001) employed the Parent Interview for Autism (PIA) (Stone & Hogan, 1993) for children younger than 3 to assess the validity and discriminative abilities of the instrument. Comparing children diagnosed with autism

to a matched group of children with non-autism-spectrum disabilities, significantly higher scores (indicating poorer functioning) were reported by parents of children with autism on behaviors relative to social relating, motor imitation and behaviors, peer interactions, imaginative play, and language understanding.

While the CHAT was described previously as an instrument containing both a parental-report component and an observational piece, the M-CHAT (Modified-Checklist for Autism in Toddlers) is strictly a 23-item, parent-report questionnaire. In testing for its accuracy in predicting an autism diagnosis, Robins, Fein, Barton, and Green (2001) used the M-CHAT to assess groups of children selected either through typical pediatric checkups (n = 1,122; age range = 18-25 months) or early intervention services (n = 171; age range = 18-30 months). After all children were screened with the M-CHAT, 58 received a follow-up evaluation because of having failed 2 or more of 8 items deemed critical discriminators (assessed through preliminary analysis of the first 600 participants) or any 3 items. Subsequently, children were categorized as either receiving (a) no follow-up (n = 1,144), (b) brief phone follow-up (n = 74), (c) an evaluation with a non-autism diagnosis (n = 19), or (d) an evaluation with an autism diagnosis (n = 39). Compared with all other groups, the children evaluated as autistic differed significantly on all screening items except 2, one of which concerned whether he/she enjoyed being bounced on one's knee and the other, whether or not he/she walked. The M-CHAT correctly classified 33 of the 38 children with autism and misclassified only 8 of the 1,196 nonautistic children. The 6 items found to be most reliably discriminant concerned interest in other children,

pointing to objects/people, bringing objects to others, imitation, responsiveness to name, and joint attention.

In a questionnaire-based investigation involving 81 families in Australia, Young, Brewer, and Pattison (in press) asked parents of children with autism to respond to both open- and closed-ended questions regarding the characteristics they first noticed as being different in their children. The earliest unusual behaviors included no interest in toys (*M* age = 9.3 months), lack of shared enjoyment (*M* age = 10.4 months), lack of eye contact (*M* age = 12 months), and disliking being cuddled or held (*M* age = 12.1 months). The most frequently reported behaviors were delayed language (*M* age = 18.4 months; 77.8% of sample), no attention to caregiver (*M* age = 17.1 months; 34.6% of sample), poor socialization (*M* age = 24.8 months; 29.6% of sample), and tantrums/crying (*M* age = 18.1 months; 28.4% of sample). Based on the closed-ended data regarding behaviors exhibited prior to 18 moths, 51.9% of the sample reported that their children seemed uncomfortable when held (*M* age = 12.8 months) and 47.4% indicated that they did not anticipate being picked up (*M* age = 16.2 months).

Factors Influencing Early Detection

Autistic regression. Parent-based descriptions are particularly helpful for researchers attempting to learn more about the phenomenon of autistic regression, or the development of autism following a period of apparently typical development. This phenomenon, which is reported to occur in 32% (Kurita, 1985) to 45% (Bernabei, Fabrizi, Paolesse, & Sogos, 1999) of children with autism, has not been well documented in the literature but is currently gaining investigative attention. In their work on maternal

perceptions of developmental regression in their children with autism, Davidovitch, Glick, Holtzman, Tirosh, and Safir (2000) interviewed 39 mothers about their children's development of gross-motor, fine-motor, social, expressive-language, receptive-language, and non-verbal language skills. Out of 40 children, 19 (47.5%) were reported to experience regression in all areas but motor skills at an average age of 24 months (*SD* = 9.43 months), with 11 children regressing before this age (considered early regressors) and 9 children (considered late regressors), after this age. In a case study focusing on a child from 24 to 38 months of age, Bernabei and Camaioni (2001) analyzed data yielded from family-home videos, parent interviews, cognitive and linguistic evaluations, and autism-diagnostic scales. They observed a marked decline in the child's social, communicative, and functional-play skills, which had appeared to be developing typically up until the beginning of his second year. Additionally, his performance on the Uzgiris-Hunt (1975) sensorimotor scales revealed a decline in mental age from 13.5 months at age 24 months to 10.2 months at age 38 months.

Williams and Ozonoff (2001) gathered information on the development of children (*N* = 60; age range of children = 3 to 9 years) with autism from parents using their newly constructed, retrospective Early Development Questionnaire (EDQ). They identified three groups of children: (a) congenital, who were reported to experience no loss of skills (*n* = 29); (b) clear regressors, who experienced a loss in both social and communicative domains (*n* = 23); and (c) unclear regressors, who experienced a loss of communication, social skills, or some other developmental component in a pattern different from the clear regressors (*n* = 8). Findings revealed that 8 of the clear-regression

group and 6 of the unclear-regression group expressed early social deficits. Approximately half of all regressors exhibited some delays prior to regression, while the remaining half regressed after a period of apparently typical development. In similar work by Werner and Munson (2001), parent reports via the authors' Early Development Interview (EDI) on their children (n = 80 for the autism group, n = 31 for the developmental delay group, and n = 39 for the typical group) were compared with home-videotapes of these children at 11 to 13 months and 24 months to assess the validity of retrospective-regressive descriptions. Based on EDI data alone, children with autism were clearly distinguished from both children with developmental delays and typically developing children. The EDI was also able to discriminate children exhibiting either consistent autistic development or autistic characteristics following a period of normal development. Videotape analyses confirmed the latter categorizations, as children who were described as regressors did not display anomalous behaviors during the 11 to 13-month videos but did in the 24-month videos. Recently, Young, Brewer, and Pattison (in press) collected questionnaire data from parents of 81 children diagnosed with autism to ascertain which characteristics initially caused them concern and at what ages. They learned that 48 (59.3%) of parents in their sample indicated that their children experienced developmental regression.

In Davidovitch et al.'s (2000) work, almost half of the children in their sample were described by mothers as developmentally regressed. Werner and Munson (2001) provided regressive versus non-regressive information via the ADI-R on 64 of their participants, noting that 17 children (27%) experienced regression. Williams and Ozonoff

(2001) categorized 31 of the 60 participating children (52%) as regressing after a period of typical development; and Young, Brewer, and Pattison (in press) revealed that almost 60% of parents in their sample indicated their children had experienced a period of typical development followed by regression. Findings such as these imply potential differences in the course that autism can take, which may create challenges in screening and diagnosing autism among infants and toddlers. Regression makes the task of sensitivity more difficult, as it will be hard to capture as positive those toddlers who do not as of yet show autistic-like symptoms. Additionally, the presence of such distinct developmental trajectories of the disorder may imply discrepant causes of autism, dependent upon either a congenital or regressive onset. DeLong (1999) hypothesized 2 forms of autism, one resulting from bilateral brain damage early in life and one not stemming from any form of neurological or biological damage but likely having a genetic basis. He further indicated that this latter, idiopathic form of autism "often has a distinct onset with regression in the second year of life, eventual higher function and some development of language, special skills or islands of normal function, prominent affective symptoms, and a better prognosis," (p. 912). More research is warranted to better elucidate the numbers of those children diagnosed with autism who expressed regressive tendencies so that we can be aware of how many may be missed in early screenings, learn more about regressive-developmental courses, and begin exploring implications of such divergent appearances of autism on causal research.

Comorbidity. A second issue that influences the early detection of autism is the potential presence of additional psychiatric disorders and/or medical conditions, and

numerous reports highlight the commonality of autism presenting alongside additional disorders. According to the *DSM-IV-TR*, 75% to 80% of individuals with autism are also diagnosed with mental retardation (APA, 2000), and this finding is considered relatively uncontroversial for classic autism (Gillberg & Billstedt, 2000). In their work examining the prevalence of other psychiatric disorders among children (n = 90) diagnosed with both mental retardation and active epilepsy, Steffenburg, Gillberg, and Steffenburg (1996) employed the Swedish Childhood Autism Rating Scale (Schopler, Reichler, Renner, Jacobsson, & Gillberg, 1988) and the Swedish Autism Behavior Checklist (Krug, Arick, Almond, & Gillberg, 1980) to identify 24 participants (27%) as having autism and 10 participants (11%) as exhibiting autistic-like behaviors. Another disorder with which mental retardation is commonly associated is Down syndrome, and some researchers have noted the likelihood for autism and Down syndrome to co-occur (e.g., Kent, Evans, Paul, & Sharp, 1999). Moreover, Capone (2002) pointed out that the risk for autism development in individuals with Down syndrome is both considerably higher than in the general population and "higher than the predicted prevalence based upon the co-occurrence of either Down syndrome (1:1000 births) or autism (est. 1:1000 births)," (p. 327). Furthermore, it is not uncommon for additional medical issues to present among individuals with both autism and Down syndrome. Rasmussen, Borjesson, Wentz, and Gillberg (2001) assessed background factors and clinical correlates among a sample (N = 25) of Swedish individuals with comorbid Down syndrome and autism, further noting that 5 participants experienced infantile seizures, 3 presented with early hypothyroidism, and 2 showed evidence of brain injury following surgery.

Other researchers have focused on the commonalities between Gilles de la Tourette's syndrome (GTS) and autism, and Barnhill and Horrigan (2002) indicated that the two probably have a common neurobiological foundation, as "the affected neural system is responsible for cognitive deficits, abnormalities in sensory gating, abnormal movements, behavioral flexibility, repetitive behaviors, self-injurious behaviors, and social-emotional interactions," (p. 7). Several investigators attest to the co-occurrence of GTS and autism, noting that the probability for the two to develop is relatively high (Baron-Cohen, Mortimore, Moriarty, Izaguirre, and Robertson, 1999; Ehlers & Gillberg, 1993; Gillberg & Billstedt, 2000). Additional literature on the comorbidity of autism and other mental or physiological disorders attests to the commonality of this phenomenon among a variety of afflictions, including depression (Ghaziuddin, Ghaziuddin, & Greden, 2002; Ghaziuddin & Greden, 1998; Gillberg & Billstedt, 2000; Lainhart, 1999), attention deficits (Bonde, 2000; Gillberg & Billstedt, 2000; Lainhart, 1999; Young, Brewer, & Pattison, in press), and even schizophrenia (Konstantareas & Hewitt, 2001; Lainhart, 1999). Likewise, some researchers reported that a significant portion, sometimes as many as half, of their participants with autism also presented with additional, identifiable genetic or neurological disorders (e.g., Chudley, Gutierrez, Jocelyn, & Chodirker, 1998; DeLong & Nohria, 1994). In a review of clinical disorders that tend to coexist with autism and Asperger syndrome, Gillberg and Billstedt (2000) outlined several medical and genetic conditions, psychological anomalies, and behavioral issues that commonly present with these diagnoses. Among those not already mentioned were epilepsy, hearing impairments, tuberous sclerosis, fragile X syndrome, difficulties with motor control and

perception, obsessive-compulsive disorder, abnormal responses to sensory stimuli, sleep problems, aggression, and self-injurious behaviors.

While it seems logical to venture that some comorbid diagnoses either share or mask autistic characteristics and assume the dominant-diagnosis position (e.g., Down syndrome, mental retardation), which appears to delay an autism diagnosis (Rasmussen, Borjesson, Wentz, & Gillberg, 2001), it is also possible that other comorbid diagnoses, particularly medical conditions (e.g., tuberous sclerosis), contribute to early detection of the disorder simply because of a historic co-occurrence of such conditions. Exactly how and which additional disorders or conditions relate to the identification of autistic characteristics in infants and toddlers, though, is not clear.

Genetics. Advances toward understanding the genetic basis of autistic characteristics are largely owed to the findings yielded from twin, adoption, and family studies. Twin analyses have revealed concordance rates for autism between 60% and 90% among monozygotic twins, while the rate for dizygotic twins is less than 5% (Rutter, Silberg, O'Connor, & Simonoff, 1999b), which suggests a strong genetic foundation. Even when twins and non-twin siblings are discordant for autism, there is a heightened risk for siblings of affected individuals to present with other pervasive developmental disorders, primarily Asperger's syndrome and PDD-NOS (Bailey, Palferman, Heavey, & Le Couteur, 1998). Scientists have further examined both the "narrow" and "broad" phenotypes of autism in relatives, the former indicating expression of impairments in at least 2 of 3 areas—social, communication, and repetitive behaviors—and the latter, impairment in at least one of these domains. Bolton et al. (1994) collected data on 137

siblings of individuals with autism and 64 siblings of individuals with Down syndrome, noting that 12.4% and 20.4% of those in the autism-sibling group presented with the "narrow" and "broad" phenotypes, respectively, compared with 1.6% and 3.1% of those in the Down syndrome-sibling group. In related work, Ghaziuddin (2000) examined these phenotypes in the parents and siblings of individuals diagnosed with comorbid autism and Down syndrome and those with only a diagnosis of Down syndrome. Sixty-four percent of the parents in the comorbid group met the criteria for the "broad" phenotype, compared with 7% of the parents in the Down-syndrome only group. Additionally, 36% of the siblings in the comorbid group presented with the "broad" phenotype, as opposed to none of those in the Down-syndrome only group. Overall, this literature suggests that first-degree relatives of individuals with autism are significantly more likely to display the both the "narrow" and "broad" phenotypes relative to family members of individuals without autism (Lainhart et al., 2002; Pickles et al., 2000; Piven, 1999; Piven, Palmer, Jacobi, Childress, & Arndt, 1997).

Researchers have also examined to what extent relatives of individuals with autism present with other psychiatric conditions. A substantial body of evidence suggests that family members, particularly parents (but to a similar extent, second- and third-degree relatives), of affected individuals are more likely to experience affective disorders (e.g., depression, anxiety disorder) relative to the general population and other parents with children experiencing disabilities (e.g., Down syndrome) and that their affective episodes originate prior to having their children with autism (Bailey, Palferman, Heavey, & Le Couteur, 1998; Bolton, Pickles, Murphy, & Rutter, 1998; Lainhart, 1999; Piven,

1999; Piven & Palmer, 1999) and especially when the diagnosis is not associated with an identifiable neurological disorder (DeLong & Nohria, 1994). In their study comparing the family histories of children with comorbid autism and depression with those of children with autism only, Ghaziuddin and Greden (1998) found that 10 (77%) of those children with the comorbid diagnosis had a parent experiencing depression compared with 3 (30%) children in the autism-only group. Similarly, Piven and Palmer (1999) discovered in their study of multiple-incidence autism families that of the 25 parents of children with autism, 16 reported experiencing a major-depressive disorder, and 12 in this group were females. While affective disorders appear to be more common in mothers and maternal relatives, as opposed to fathers, of individuals with autism (Bailey, Palferman, Heavey, & Le Couteur, 1998; Bolton, Pickles, Murphy, & Rutter, 1998; DeLong & Nohria, 1994; Piven & Palmer, 1999), some evidence suggests that a paternal-family history of schizophrenia is also frequently reported (Chudley, Gutierrez, Jocelyn, & Chodirker, 1998). Additionally, researchers have noted that the incidences of motor tics and obsessive-compulsive disorder are higher in family members of individuals with autism versus those of individuals with Down syndrome (Bolton, Pickles, Murphy, & Rutter, 1998).

In related vein, molecular geneticists have sought the direct contribution of genes to the development of autism. Results in this arena are preliminary, but some investigations point both to chromosome 15 and the X chromosome as hosting susceptibility genes for autism (Gillberg & Billstedt, 2000). Other researchers reliably reported autism-related anomalies on chromosome 7 but also noted that several genetic

deviations likely contribute to the disorder (Rutter, Silbert, O'Connor, & Simonoff, 1999b). In a review of the literature on molecular-genetic risk factors in autism, Lauritsen and Ewald (2001) reported that the most promising results are yielded from studies examining chromosomes 7q31-35, 15q11-13, and 16p13.3. Research in this arena is still young; however, it is likely that over the next several years molecular-genetics studies will be able to tell us much more about the origins of autism-spectrum disorders.

Conclusion

Overall, the literature attests to the existence of autistic characteristics in populations younger than 3, the approximate age at which confident diagnoses are currently made. While evidence supports better detection of such differences during the second year of life (12-24 months), some reports reveal developmental anomalies present during the first year. Various methods (e.g., family-home videos, screening devices, parent reports) of obtaining information on the early development of children with autism yield remarkably congruent findings. Characteristics commonly noted across methods include lack of eye contact; affective differences; lack of social skills, including imitative acts and joint-attention behaviors; postural/motoric/gestural differences; unresponsiveness to others and/or one's name; an absence of attention-seeking behaviors; solitary or unusual play patterns; and communication delays.

Such complimentary findings offer promise in delineating early signs of autism for screening and diagnosis with infants and toddlers. Earlier and more accurate detection subsequently aids in the identification of autism with young populations, rendering them eligible for intervention services. Because significant delays in detection have adverse

effects for both children's developmental outcomes and their families' abilities to cope with disorder, continued efforts at targeting and confirming early symptoms of autism are imperative to mitigating the immediate (for affected children) and indirect (for children's families) effects of autistic disorder.

Early detection of autistic characteristics, however, may be impeded or exacerbated by certain factors, and we know little about *which* factors influence detection and *how*. One obvious variable in the equation is developmental regression, which logically hinders our ability to detect at-risk children during infancy and early toddlerhood simply because they do not yet express anomalous behaviors. Regression is an observable phenomenon that may occur in as many as half of all children who develop autism, and some researchers theorize that regressive development of autism implies a different causal mechanism from that of congenital autism. Therefore, a closer examination of developmental regression and how it may interact with other potentially influential variables is warranted. A second factor that seems likely to affect the early detection of autistic symptoms is comorbidity. Numerous studies highlight the commonality of additional medical and psychological disorders presenting in conjunction with autism, some of which may share features of autism (e.g., Tourette's syndrome) and others which appear very different (e.g., Down syndrome). For this reason, it seems probable that comorbid diagnoses impact the way that we view emerging characteristics of autism by either masking or exacerbating symptoms, which subsequently colors detectability. A third factor that plays a role in risk for autism is genetic, or specifically, whether or not there is a family history of autism-spectrum or other mental-health

disorders among relatives. Several studies indicate that autism-spectrum disorders and the broader autism phenotype tend to run in families. Moreover, there is evidence to suggest that parents of children with autism commonly present with affective disorders, particularly mothers. It is possible that parents who are familiar with the early signs of autism because of another family member's diagnosis notice symptoms at earlier ages relative to those parents without a diagnosed family member. However, it is also possible that a family history of mental-health disorders, particularly in the parents of diagnosed children, works in conjunction with other factors (e.g., regressive versus congenital onset) to impact detection of early characteristics. Exactly how these factors affect, both independently and in conjunction with each other, detectability of early autism characteristics, though, is unknown.

A final consideration is parents' construction of beliefs about autism in their own child. A constructivist point of view suggests that beliefs do not grow in a straightforward way out of objective facts but rather are cognitive constructs that individuals build and that are based on personal, cultural, educational, and experiential pieces. These constructions are more than objective factoids. They are the meanings that people create. These meanings are produced for all components of life. Here, we are interested in the meanings that parents create about autism in their own children.

The purpose of the proposed investigation was to (a) better understand how parents view the development of autism in their children, specifically early characteristics of the disorder; (b) document potential commonalities within parents' reports of the emergence of autistic symptoms in their children among a large sample; and (c) report the

frequencies of early characteristics of regressive tendencies, comorbidity, and family history of mental-health disorders and the potential impact of parents' beliefs about the causes of autism. The following hypotheses were proposed:

1. Participants who report larger incomes and greater education will also report noticing early characteristics of autism in their children at younger ages.
2. Participants who suggest that their children exhibited congenital autism will report noticing characteristics of the disorder in their children at earlier ages relative to participants who indicate that their children experienced regression.
3. Participants who suggest that their children exhibited congenital autism will be more likely to espouse a genetic etiology of the disorder, while participants who report developmental regression in their children will be more likely to attribute the disorder to some external mechanism.
4. Participants' beliefs about the etiology of autism will be influenced by where they get information about autism, so that participants who report a congenital onset will more often report getting information from professional sources, such as journals, whereas those who report a regressive onset will more often report getting information from less professional sources, such as websites.
5. Comorbidity is more likely to be reported in children who exhibited congenital autism.
6. Participants who report comorbid diagnoses in their children will also have noticed quantitatively more characteristics.

7. Participants will report noticing characteristics at earlier ages when there is a family history of mental-health disorders.
8. Participants will notice quantitatively more characteristics when there is a family history of mental-health disorders.
9. Participants will notice characteristics at earlier ages when they report collectively a congenital onset of autism, comorbidity, and a family history of mental-health disorders.

Method

Participants

Parents and other caregivers who have a child with autism were invited to respond to a web-based questionnaire through newsletters and websites of autism organizations. Thus, no individual or family was contacted directly. Initially, we targeted only those families living in the Commonwealth of Virginia. Organizations deemed appropriate were originally selected from a list provided by The Autism Program of Virginia. In August 2002, these groups were sent a letter (Appendix A) via e-mail, fax, and/or mail to ask for their cooperation in posting an advertisement (Appendix B) describing the investigation on their websites, newsletters, and e-mail lists. We asked that they advertise the study on as many venues as they maintain (e.g., both in a hard-copy newsletter and an e-mail distribution) so as to target as many individuals as possible. If no response was received from an organization representative, that organization was contacted again by e-mail or telephone. Incoming data from families were tracked to ascertain the rate of participation, which can be seen in Table 2.

Table 2

Rate of Participant Response

Date	Total Number of Responses	New Responses
September 18, 2002	14	-
October 15, 2002	27	13
October 29, 2002	86	59
November 13, 2002	159	73
November 25, 2002	205	46
December 18, 2002	260	55
January 10, 2003	296	36
January 30, 2003	357	61
February 10, 2003	372	15
February 24, 2003	392	20
March 18, 2003	419	27

In October 2002, advertisements for the study were sent to an expanded list of autism-related organizations across the United States and in 7 other English-speaking countries. Most organizations contacted in the United States were chapter affiliates of the Autism Society of America, a national organization offering support and resources for families of individuals with autism. Organizations outside of the United States were selected from an international list of autism-related associations provided by the National Autistic Society. Only those organizations from predominantly English-speaking nations

were chosen for inclusion. Appendix C contains a list of these organizations, whether or not their representatives confirmed receipt of the advertisement request, and through which venues they indicated advertising the study. Because of the number of responses received from locations in which study advertisement was not confirmed, it is believed that many of these organizations advertised the study but did not reply as such. While it is possible that participants learned of the investigation through word-of-mouth and/or by browsing autism sites on the Internet, we only advertised through the abovementioned means and anticipated that the majority of participants were members of the targeted organizations. Cooperation with the project was both voluntary and anonymous.

Participants included 393 caregivers of children with autism, most of which were mothers (89.8%). Their average age was 38.1 years (*SD* = 7.1, range = 23 to 72 years) and their average level of educational attainment was 15.3 years (*SD* = 2.4, range = 9 to 26 years), the latter of which indicated that most had some collegiate experience. In terms of approximate family income, the highest percentage of individuals (*n* = 74, 19.6%) reported incomes at or greater than $100,000 per year. Participants represented almost every state in the U. S. as well as the countries of Australia, Canada, England, Ireland, and New Zealand. Most reported their race as white (*n* = 348, 89%) and the majority were married at the time they completed the questionnaire (*n* = 324, 82.9%). Additional demographic information on caregivers can be found in Table 3, and frequencies regarding families' locations are provided in Table 4.

Table 3

Participant Demographics

Variable	Frequency (%)
Gender	
Female	358 (91.6%)
Male	33 (8.4%)
Age (total)	*M* = 38.1 years, *SD* = 7.1, range = 23 to 72
Female	*M* = 37.7 years, *SD* = 7.1, range = 23 to 72
Male	*M* = 41.9 years, *SD* = 6.3, range = 34 to 57
Education (total)	*M* = 15.3 years, *SD* = 2.4, range = 9 to 26
Female	*M* = 15.2 years, *SD* = 2.4, range = 9 to 26
Male	*M* = 15.8 years, *SD* = 2.6, range = 10 to 21
Income (in thousands of U.S. $ per year)	
< $10	6 (1.6%)
between $10 - $25	38 (10.1%)
between $25 - $40	70 (18.6%)
between $40 - $55	57 (15.1%)
between $55 - $70	62 (16.4%)
between $70 - $100	70 (18.6%)
> $100	74 (19.6%)
Race	
Asian	11 (2.8%)

Australian/New Zealander	1 (0.30%)
Bi-racial/Mixed	6 (1.5%)
Black/African American	6 (1.5%)
Hispanic/Latino	12 (3.1%)
Middle Eastern	2 (0.50%)
Native American	2 (0.50%)
White	348 (89%)
Other	3 (0.8%)
Marital Status	
Divorced	30 (7.7%)
Married	324 (82.9%)
Separated	11 (2.8%)
Single	23 (5.9%)
Widowed	3 (0.80%)
Relationship to Child	
Mother	351 (89.8%)
Father	32 (8.2%)
Step-mother	6 (1.5%)
Grandmother	1 (0.30%)
Professional working with child	1 (0.30%)

Table 4

Families' Locations

Location	Frequency (%)	Location	Frequency (%)
U.S. (total)	300 (76.3%)	AK (Alaska)	5 (1.3%)
AL (Alabama)	5 (1.3%)	AR (Arkansas)	4 (1.0%)
AZ (Arizona)	1 (0.3%)	CA (California)	40 (10.2%)
CO (Colorado)	3 (0.8%)	CT (Connecticut)	2 (0.5%)
DE (Delaware)	3 (0.8%)	FL (Florida)	6 (1.5%)
GA (Georgia)	6 (1.5%)	HI (Hawaii)	1 (0.3%)
ID (Idaho)	1 (0.3%)	IL (Illinois)	10 (2.5%)
IN (Indiana)	13 (3.3%)	IO (Iowa)	1 (0.3%)
KS (Kansas)	5 (1.3%)	KY (Kentucky)	3 (0.8%)
LA (Louisiana)	6 (1.5%)	MA (Massachusetts)	1 (0.3%)
MD (Maryland)	16 (4.1%)	MI (Michigan)	5 (1.3%)
MN (Minnesota)	5 (1.3%)	MO (Missouri)	5 (1.3%)
MS (Mississippi)	2 (0.5%)	MT (Montana)	1 (0.3%)
NB (Nebraska)	1 (0.3%)	NC (North Carolina)	4 (1.0%)
NH (New Hampshire)	2 (0.5%)	NJ (New Jersey)	6 (1.5%)
NM (New Mexico)	9 (2.3%)	NV (Nevada)	3 (0.8%)
NY (New York)	11 (2.8%)	OH (Ohio)	23 (5.9%)
OK (Oklahoma)	2 (0.5%)	OR (Oregon)	1 (0.3%)
PA (Pennsylvania)	8 (2.0%)	SC (South Carolina)	6 (1.5%)

SD (South Dakota)	2 (0.5%)	TN (Tennessee)	10 (2.5%)
TX (Texas)	15 (3.8%)	UT (Utah)	1 (0.3%)
VA (Virginia)	35 (8.9%)	WA (Washington)	7 (1.8%)
WI (Wisconsin)	3 (0.8%)	WV (West Virginia)	1 (0.3%
Australia	9 (2.3%)	Canada	29 (7.4%)
England	22 (5.6%)	Ireland	5 (1.3%)
New Zealand	8 (2.0%)	Unselected/Unknown	20 (5.1%)

Materials

Data were collected via a questionnaire (see Appendix D) posted on the World Wide Web. The first page of the website described the investigation and outlined informed consent (see Appendix E). The questionnaire was divided into 7 sections: (a) child demographics, (b) diagnostic information, (c) early characteristics and age of appearance, (d) informational and personal-support resources, (e) treatments and perceptions of effectiveness, (f) participant (caregiver) demographics, and (g) qualitative descriptions of caregivers' perceptions of both their child's development and family life. For the purposes of this investigation, we focused primarily on responses provided in the sections concerning (a) demographic information of both caregiver and focal child, (b) early characteristics of the disorder and age of appearance (including regressive tendencies), (c) comorbid diagnoses, and (d) family-history of mental-health disorders.

This web-based questionnaire was developed originally in the same way as that of a paper-and-pencil questionnaire, undergoing numerous drafts. Input was sought from 2 mothers of children with autism (1 with a teenage son and 1 with 2 elementary-school aged daughters) to make sure that the questionnaire both contained important queries that sensitively targeted families' experiences with their children with autism and was easy to understand and complete. The design of the questionnaire largely follwed Dillman's (2000) suggestions regarding simplicity of web-based questions and question formats, reserved use of color on the web, and minimal use of drop-down and "check all that apply" answer choices. One potential difficulty with the computer-screen presentation of the questionnaire was that participants may have viewed the structure of questions and

answer choices differently because of various browser settings, which was an irresolvable limitation.

An undergraduate psychology major who worked in the computer-services office for the College of Humanities and Sciences was hired to build the website, post the questionnaire, and develop the database. Space on the university network server was secured for the study through the Office of Information Technology, which subsequently designated the questionnaire's website address. The Microsoft© programs, FrontPage© and Access©, were used to develop the webpage and database, respectively. These software programs are designed to work together for such Internet-survey purposes.

The web-based questionnaire method was chosen because (a) the questionnaire was available to an audience larger than that which would otherwise be targeted from mailing lists of autism-related organizations; (b) it was inexpensive, as copying and mailing of questionnaires are unnecessary; (c) the step of data entry by the researcher was largely omitted because data were submitted electronically; (d) data-input errors were decreased; and (e) processing of results was faster because of electronic-data submissions.

Procedure

The study was approved by the University's institutional review board prior to advertising or posting the questionnaire on the website. When potential participants located the questionnaire website, they were provided with a description of the investigation, informed-consent information, and given the option of moving on to the questionnaire. After completing the questionnaire, participants were questioned as to

whether or not they would like to submit it. All submitted responses were automatically transferred to a database for later statistical analysis. Following analyses, a summary of the results were provided to the contacted autism-related organizations for them to post on their websites, e-mail lists, and in their newsletters so that participants and others may view the findings.

Analyses

Quantitative analysis. The questionnaire was designed to yield descriptive information regarding the experiences and perceptions of families with a child who has autism. Variables selected to describe the participants and their children included the gender, age, and race of both caregiver and child; setting in which the child lives; settings in which the child spends his/her day; type of school the child attends; child's primary diagnosis in the autism spectrum; child's secondary diagnoses; at what age the child received a diagnosis in the autism spectrum; who made the diagnosis; caregiver's marital status, educational attainment, level of income, and relation to the child; and the family's locale. Frequencies regarding the early characteristics of autism and the average ages at which parents indicate noticing such characteristics were also reported. Additional analyses may be seen in Table 5, alongside corresponding hypotheses.

Table 5

Hypotheses, Selected Variables, and Analyses

Hypothesis	Variables	Analysis
1. Participants who report larger incomes and greater education will also report noticing early characteristics of autism in their children at younger ages.	participant income; participant education level; early-characteristic ages	Pearson *r*
2. Participants who suggest that their children exhibited congenital autism will report noticing characteristics of the disorder in their children at earlier ages relative to participants who indicate that their children experienced regression.	congenital vs. regressive; early-characteristic ages	one-way ANOVA's
3. Participants who suggest that their children exhibited congenital autism will be more likely to espouse a genetic etiology of the disorder, while participants who report developmental regression in their children will be more likely to attribute the disorder to some external mechanism.	congenital vs. regressive ; belief about etiology	chi-square
4. Participants' beliefs about the etiology	information source;	chi-square

of autism will be influenced by where they get information about autism, so that participants who report a congenital onset will more often report getting information from professional sources, such as journals, whereas those who report a regressive onset will more often report getting information from less professional sources, such as websites.	belief about etiology	
5. Comorbidity is more likely to be reported in children who exhibited congenital autism.	presence vs. absence of comorbidity; congenital vs. regressive	chi-square
6. Participants who report comorbid diagnoses in their children will also have noticed quantitatively more characteristics.	presence vs. absence of comorbidity; early characteristics	t-test for unmatched samples
7. Participants will report noticing characteristics at earlier ages when there is a family history of mental-health disorders.	early-characteristic ages; family history	t-test for unmatched samples

8. Participants will notice quantitatively more characteristics when there is a family history of mental-health disorders	early characteristics; family history	t-test for unmatched samples
9. Participants will notice characteristics at earlier ages when they report collectively a congenital onset of autism, comorbidity, and a family history of mental-health disorders.	early-characteristic ages (DV); congenital vs. regressive (IV); presence vs. absence of comorbidity (IV); family history (IV)	Stepwise-linear regression

Qualitative analysis. Three open-ended questions were the foci of qualitative analysis: (a) "Do you feel that your child has always had characteristics of autism, or did they develop after a certain point or age? Please describe." (b) "Do you ever notice your child making developmental improvements and then regressing, apparently "forgetting" new skills? If so, please describe." (c) "What is your personal theory of what causes autism, at least in your own child?" These data were inductively analyzed using Strauss and Corbin's (1990) three-level coding process. The technique involves (a) scanning the raw data for and categorizing emergent themes (open coding), (b) searching for clues that connect ideas and looking for cases that do not fit existing categories (axial coding), and (c) refinement and organization of final categories (selective coding). Codes were assigned to participants' responses to these 3 questions so that their relationships with additional quantitative variables could be assessed. These codes were determined collectively by the first and second authors (the latter of which was the dissertation advisor). In every instance, participant viewpoint was respected as to the onset and nature of autism in his or her child.

As a validity check for the qualitative coding, the second author, 2 mothers of children with autism, and 1 professional in the field of autism who had regular contact with children experiencing autism and their families examined a random sample of 80 participants' open-ended responses (20%) to ensure both (a) the veracity of participants' descriptions regarding life with a child experiencing autism and (b) that the final coding categories accurately represented their answers. A website-based, random-number generator (www.random.com) was used to select those participants whose responses were

used in this process. Each of the 3 validity checkers received a copy of the qualitative responses, codes assigned to responses, and an instruction sheet on how to check the validity of codes (Appendix F). Any interpretive discrepancies that arose were settled through discussion upon return of the materials to the first author.

Results

Qualitative Results

Response codes were generated for each participant's answers to 3 open ended questions. Tables 6 (questions #25 and #26) and 9 (#27) indicate the question asked, the codes given to responses for that question, a brief description of that code, and examples from the raw data to support such classification.

Table 6

Initial Qualitative Coding Scheme for Questions #25 and #26

Question	Code and Definition	Quoted Examples
#25 "Do you feel that your child has always had characteristics of autism, or did they develop after a certain point or age?"	1. Always = Believes that autism characteristics were present from birth or very early on in life	"I think that my son always had autism - in looking back at family movies, pictures, etc. he seemed to have the characteristics of autism from a very young age."
		"Yes. Very early, she was extremely hyper-active at age 6 months. I noticed a clumsiness about the way she moved. She would hyper-focus on certain things like babies or horses and became very demanding about being around them."
	2. Not always = Believes that autism characteristics only or largely developed following a certain age and/or event	"No. My son walked, crawled, etc., all on time. He had good eye contact, played with toys, etc. He began to develop words, mama, paw paw, bottle, bye bye, stop. Between 15 and 24 months this all

		changed beginning with no more speech development to no speech at all by age 2. Between 18 and 24 months we also lost eye contact, appropriate play, etc."
		"I believe in my heart he was not born with autism. My son's development was 'right on'. I had two older children and was familiar with developmental milestones. Shortly after the age of 1, my son regressed more and more as the months passed."
	3. Not sure = Participant is unsure of when autism characteristics began	"I'm not sure. He seemed to be normal up to six months. I didn't notice anything dramatic. It seemed just to be a case of late language development in his first year."
		"I can't truly be sure. He was always quirky, but I don't know when I really noticed the quirkiness. He was a very calm

		baby and slept very well. He was very active in utero."
	4. Unclear = Authors were unable to determine participant's response	"Other people used to ask me if she was hard of hearing when she was 18 months old." "I had no idea until Early Intervention services final report, then I put the pieces together after visiting websites."
#26 "Do you ever notice your child making developmental improvements and then regressing, apparently 'forgetting' new skills?	1. Yes = Yes, the child has regressed or does periodically regress	"Improvement in behavior and social skills would appear and then regress. We are constantly teaching and re-teaching social and behavior skills." "Yes, especially with language... he may just start saying new words and then it's like he forgets the words or how to say things."
	2. No = No, the child has not exhibited regression	"My son never regressed. He just never spoke." "We haven't noticed that at all

		fortunately.”
	3. Unclear = Authors were unable to determine participant’s response	“This one is difficult one to say. Because he thought what he was doing was normal and proceed his life that way. But now realizing, perhaps it was too late for him, he must struggle with this every day. We are trying to get him help but he is getting older.” “He has toileting problems and occasionally get lazy about asking for things. He points when he is capable of talking.”

The first open-ended question (#25) was asked to generate participants' beliefs about whether or not autism was a either a congenital or an acquired condition in their children. In most cases, participants indicated clear beliefs that it was either always present or it developed following a period of seemingly typical development. Some participants were unsure of when characteristics first began, and a few responses were unclear to the point that their opinions on this issue could not be determined.

The second open-ended question (#26) inquired about the regressive nature of autism in participants' children. Again, most individuals either stated plainly that this did or did not occur; however, in many cases where regression was reported, participants included descriptions about specific types of regression. In some instances, regression was described as a one-time event that coincided with the onset of autistic characteristics and no subsequent indications of regressive tendencies were reported. Other participants stated that their children regressed periodically but only in one area of development, usually language, academics, or toileting. Still others suggested that their children either had experienced regressive episodes prior to a therapeutic program (such as Applied Behavior Analysis or the Picture Exchange System) and/or that regressive incidences were mitigated through constant reinforcement or maintenance of desired skills. Finally, many participants described regression as a regular event that had global effects on their children, presenting as deterioration across a variety of skills and behaviors (e.g., language, toileting, eating, overall compliance). In contrast, some participants responded to this question with a description of newly acquired oddities in their children's behavior versus a loss of skills. These new behaviors were typical of those expressed by

individuals with autism and may have been viewed as more infantile and problematic relative to those of unaffected individuals. Thus, the phenomenon of developmental regression meant somewhat different, albeit related, things to different parents. Interestingly, it was not always viewed from a negative slant, although it undoubtedly represented setbacks for children. Several individuals noted that their children tended to regress jut prior to making a significant developmental improvement, thus for some it was a sign that something positive was about to happen, as one participant eloquently stated:

> "A developmental breakthrough is often followed by a period of regression, but I would not describe it as 'forgetting new skills.' I see it more as a pendulum which, having been moved in one direction (improvement), naturally swings back in the other direction (regression). The regression, then, is as much a sign of progress as the improvement. In addition, we have often observed periods of difficulty/regression immediately preceding a noticeable improvement in our daughter's abilities. The pendulum swings both ways, but it is the movement that is important, not just the direction."

Whenever necessary to help clarify a participant's response to one of the 3 open-ended questions, responses from 1 or both of the remaining 2 questions were considered so that a clear determination could be made for his or her answer. Table 7 contains an example of one participant's responses to these questions; codes are provided in parentheses following these quotes. In this case, information within the answer to question #25 helped to confirm the classification of regression in question #26, as it was

clearly indicated that problems began to develop after a certain age, which implies a regressive onset. Behaviors indicated in the answer to question #26 suggested mild regressive tendencies, but the response in #25 bolsters this perception. In several cases, participants clearly described a regressive onset of autism in their responses to #25 but would then indicate that their children had not experienced regression in #26. Parents may have responded in this way to suggest that their child has not regularly experienced regression outside of the initial onset. However, these cases were recoded to reflect the fact that they had experienced regression, albeit at one major point.

Table 7

Example: Code Clarification

#25	#26	#27
I feel that my child was fine until he received his first MMR shot at the age of 11 months. He started having problems at age 15 months. (not always)	My child will do great in a particular social setting, like eating in a restaurant, then the next time we try it, he doesn't like it at all. It also the same way with him going to school. (yes)	I believe that autism may be hereditary, but I also think that the mercury in the vaccinations has a lot to do with it, too. (genetics + external trigger)

Codes to questions #25 and #26 were combined to create a new variable indicating (a) whether autism was viewed as having a congenital or regressive onset (always or did not always have characteristics) and (b) whether or not regression,

associated with onset and/or as a regular phenomenon, was seen as a part of the child's experience with autism. By far, the most frequent responses were that children did not always present with autism characteristics and had experienced developmental regression (n = 156, 47.6%), that children always had symptoms of autism and never experienced regression (n = 73, 22.3%), or that children always had symptoms of autism and periodically experienced regression (n = 72, 22.0%). With the latter 2 groups of "always had autism" combined, it appears that approximately half of respondents believed autism was always present in their children and the remaining half believed that autism only developed after a certain age or event in the child's life. Table 8 further delineates created codes, their explanations, and their frequencies.

Table 8

Congenital- vs. Regressive-Onset Codes (*n* = 328)

Code	Description	Frequency (%)
AN	Always had autism/Never regressed	73 (22.3%)
AU	Always had autism/Unclear regarding regression	3 (0.9%)
AY	Always had autism/Experienced regression	72 (22.0%)
NAN	Did not always have autism/Has not experienced regression	2 (0.6%)
NAU	Did not always have autism/Unclear regarding regression	2 (0.6%)
NAY	Did not always have autism/Experienced regression	156 (47.6%)
NSU	Not sure about autism onset/Unclear regarding regression	1 (0.3%)
NSY	Not sure about autism onset/Experienced regression	2 (0.6%)
UN*	Unclear regarding autism onset/Has not experienced regression	8 (2.4%)
UU*	Unclear regarding autism onset/Unclear regarding regression	1 (0.3%)
UY*	Unclear regarding autism onset/Experienced regression	8 (2.4%)

* "Unclear" refers to the respondent's answers being either inconsistent or not clearly answering the question.

The final open-ended question (#27) concerned participants' beliefs about the cause of autism in their children. Answers to this question varied considerably; however, the majority of responses indicated a belief in either a genetic cause, external triggers (e.g., vaccinations, environmental toxins), or a combination of these two. In many instances, participants illustrated uncertainty in their responses, often using terms such as "maybe" or "possibly," suggesting that they had ideas about causes but that they were not foregone conclusions. Table 9 illustrates the final categories into which responses were coded, a description of that code, and examples from the raw data to support such classification. Table 10 provides the frequencies of responses for each of these final categories.

Table 9

Qualitative Coding Scheme for Question #27

Question: "What is your personal theory of what causes autism, at least in your own child?"		
Genetic	Implicates genes, heredity, or family history of autism/mental-health disorders	"Genetics. Her paternal grandmother has similar symptoms but has never been diagnosed." "I believe that we have a genetic predisposition on both sides of the family. I have 3 family members who are bipolar in my immediate family (mother and siblings), and my father also suffers from depression. My husband has a father who is socially odd, but has learned to navigate the world in a mostly rote way."
External	Implicates vaccines/immunizations/shots	"He was SO normal before

	medications, environmental toxins, or other external/environmental triggers	hand I am fairly certain it was caused from his immunizations." "He was born in Toms River, NJ, right next door to Brick Town which has a high incident of autism, I think it is the enviroment where we lived in central Jersey. We lived in between a chemical plant and Ciba Giegy chemical plant."
Genetic + External	Implicates a combination of genetic and external factors	"Children are genetically predisposed and all the autistic symptoms are aggravated by mercury in vaccines and other environmental injuries." "Genetic predisposition acted upon by some environmental source. I

		don't think vaccines caused J's autism, but I think they played a role…I think the genetic markers had to be there first, otherwise every kid would end up autistic."
Biological	Implicates physiological or neurological factors, including immune deficiencies, metabolic issues, chemical imbalances, physical illnesses/allergies, medical conditions, and brain development	"Immune insult. Both of my children with autism have highly elevated natural killer cells, as if their bodies are still fighting an 'infection'." "He developed croup at 3 mos. old, and had to be hospitalized in ICU on a ventilator for 4 days because his airway swelled shut. I believe that this illness triggered something, because up until then he was that age he smiled and cooed normally."

Genetic + Biological	Implicates a combination of genetics and biological factors	"I believe that it is a metabolic issue and that equally important, there is a genetic component." "I think people are genetically predisposed, and then something, probably prenatal, triggers the changes in brain structure that characterize autism."
External + Biological	Implicates a combination of external and biological factors	"I think that his digestive system may have been immature and that he may have had casein allergies which contributed to the heavy metal build up from his vaccines. However, he experienced a major regression immediately following his 3rd DPT/MMR."

		"My family has a history of immune problems. I believe the MMR shot overloaded his immune system and caused damage."
Other	Implicates factors that include social influences, maternal illness/distress or medications, prenatal/birth difficulties, newborn medical/early childhood trauma, "God"/destiny/by chance	"Trauma at birth." "I think for my child it may be the contrast of having 2 caregivers with very different child rearing manners. Being treated like a king and not having to have to communicate vs. a more strict approach. Perhaps too many video's and not enough constructive interaction while my husband & I are working."
Multiple	Implicates a combination of factors, either several (more than 3) or some	"I believe that my son may have been exposed to

	combination of “Other” factors with “Genetic,” “External,” “Biological” factors and/or with the combination factors of these latter 3 categories	something toxic during my pregnancy as his cousin born the same year also has autistic tendencies and was born in the same town. The pregnancy was difficult and he was born with a trigonocephaly and experienced pressure both in womb and after surgery to this skull particularly in the frontal area.” “A culmination of things. In my child’s case I believe it was vaccine, genetics, and maybe other factors.”

Don't know	Does not have a personal theory of causation	"Have no clue." "I honestly do not know."
Unclear/Unsure	Vacillates between causes, or authors were unable to determine code based on response	"Lord knows. Maybe vaccinations, maybe gene combo, maybe too much tuna." "Either born with it or caused by MMR vaccine. I can't decide."

Table 10

Frequencies of Responses Pertaining to Perceptions of Causation by Final Category

Type of Cause	Frequency
Genetic	*n* = 82 (25.3%)
External	*n* = 56 (17.3%)
Genetic + External	*n* = 46 (14.2%)
Biological	*n* = 25 (7.7%)
Genetic + Biological	*n* = 12 (3.7%)
External + Biological	*n* = 7 (2.2%)
Other	*n* = 12 (3.7%)
Multiple	*n* = 28 (8.6%)
Don’t know	*n* = 38 (11.7%)
Unclear/unsure	*n* = 18 (5.6%)

Quantitative Results

Descriptive Information. Participants described their children who experience an autism-spectrum disorder, 320 (81.8%) of whom were male and 71 (18.2%) of whom were female. Children's average age was 8.5 years (*SD* = 4.8, range = 1.9 to 36), and the majority were described as white (*n* = 335, 85.2%) and residing at home with their parents (*n* = 384, 97.7%). Most spent the bulk of their days at home (*n* = 244, 62.1%) and at school (*n* = 245, 62.3%), and 46 (11.7%) were said, per open-ended responses, to spend time in other settings that included therapeutic programs, relatives' homes, and community/social outings. For those children attending schools, either public or private, 143 (36.5%) were educated in mainstream (inclusive) classrooms while 146 (37.2%) were educated in special-education classrooms. Additional demographic information on children can be found in Table 11.

Table 11

Children's Demographics

Variable	Frequency (%)
Gender	
Female	71 (18.2%)
Male	320 (81.8%)
Age (total)	*M* = 8.5 years, *SD* = 4.8, range = 1.9 to 36
Female	*M* = 9.5 years, *SD* = 5.2, range = 2.8 to 30.8
Male	*M* = 8.2 years, *SD* = 4.6, range = 1.9 to 36
Race	
Asian	4 (1%)
Australian/New Zealander	3 (0.8%)
Bi-racial/Mixed	29 (7.4%)
Black/African American	6 (1.5%)
Hispanic/Latino	9 (2.3%)
Middle Eastern	2 (0.5%)
White	335 (85.2%)
Other	5 (1.3%)
Residence	
Grandparent's/relative's home	1 (0.3%)
Group home	4 (1.0%)
Parent's home	384 (97.7%)

School/treatment center	2 (0.5%)
Other setting	2 (0.5%)
Where children spend their days*	
Home	244 (62.1%)
Childcare/babysitter	38 (9.7%)
Preschool/nursery school	89 (22.6%)
Elementary, middle, or high school	245 (62.3%)
Day-treatment center	18 (4.6%)
Sheltered workshop	2 (0.5%)
Vocational training/college	10 (2.5%)
Job/supportive employment	5 (1.3%)
Other setting	46 (11.7%)
Type of school attending	
Inclusive classroom	143 (36.5%)
Special-education classroom	146 (37.2%)
Special school exclusively for children with special needs	62 (15.8%)
Vocational training/technical school	5 (1.3%)

* Participants could choose more than one setting in which their children spent their days (e.g., at home and at school).

In terms of diagnoses within the autism spectrum, 248 children (63.1%) had been diagnosed with autism, 76 (19.3%) with Asperger's syndrome, 54 (13.7%) with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), 1 (0.3%) with Childhood Disintegrative Disorder (CDD), and 14 (3.6%) with no definitive label. Most children (*n* = 172, 46%) had been diagnosed by a specialist doctor (e.g., neurologist, developmental pediatrician); however, 87 (23.3%) were diagnosed by psychologists, 48 (12.8%) by psychiatrists, 38 (10.2%) by multidisciplinary teams of professionals, 6 (1.6%) by a primary-care physician or family doctor, and 23 (6.1%) by some other professional, usually someone affiliated with the educational system (e.g., teacher, speech pathologist at school, occupational therapist). More descriptive information regarding diagnoses, ages of children within diagnoses, and ages at which diagnoses were made is provided within Table 12.

Table 12

Autism-Spectrum Diagnostic Information

Diagnosis	Current Age Demographics	Age of Diagnosis
Asperger's	*M* = 10.7 years, *SD* = 4.0, range = 4.9 to 21.9 (*n* = 76)	*M* = 7.5 years, *SD* = 3.5, range = 2.8 to 16.8 (*n* = 73)
Female	*M* = 11.3 years, *SD* = 4.4, range = 4.9 to 21.9 (*n* = 16)	*M* = 8.9 years, *SD* = 4.1, range = 3 to 15.3 (*n* = 15)
Male	*M* = 10.4 years, *SD* = 3.8, range = 5.2 to 20.2 (*n* = 59)	*M* = 7 years, *SD* = 3.2, range = 2.8 to 16.8 (*n* = 57)
Autism	*M* = 8.1 years, *SD* = 5.0, range = 2 to 36 (*n* = 248)	*M* = 3.5 years, *SD* = 2.1, range = 1.2 to 30.8 (*n* = 245)
Female	*M* = 9 years, *SD* = 5.5, range = 2.8 to 30.8 (*n* = 45)	*M* = 4.1 years, *SD* = 3.4, range = 2.8 to 30.8 (*n* = 45)
Male	*M* = 7.9 years, *SD* = 4.9, range = 2 to 36 (*n* = 202)	*M* = 3.4 years, *SD* = 1.7, range = 1.2 to 15 (*n* = 200)
CDD		
Male	12.1 years (*n* = 1)	2.8 years (*n* = 1)
PDD-NOS	*M* = 7.8, *SD* = 4.0, range = 2.5 to 19.9 (*n* = 54)	*M* = 4.5 years, *SD* = 3.5, range = 1.5 to 24.3 (*n* = 54)
Female	*M* = 8.6 years, *SD* = 4.4, range = 4.6 to 18.5 (*n* = 10)	*M* = 5.9 years, *SD* = 2.7, range = 2 to 10 (*n* = 10)
Male	*M* = 7.6 years, *SD* = 4.0, range = 2.5	*M* = 4.2 years, *SD* = 3.6, range =

to 19.9 (n = 44)	1.5 to 24.3 (n = 44)

Participants further indicated additional diagnoses outside of the autism spectrum that their children had received. The questionnaire specifically queried potential comorbid diagnoses of ADD/ADHD, brain damage, mental retardation, seizure disorder, Sensory Integration Processing Disorder, and tuberous sclerosis but also allowed for participants to indicate other diagnoses. Participants had the option of selecting both closed-ended diagnoses and providing additional, unlisted diagnoses. While 101 participants (25.7%) indicated that their children experienced an additional diagnosis of some other disorder not listed, it was determined that responses from only 74 of these participants (18.8%) were valid, as many indicated a previously diagnosed autism-spectrum disorder (e.g., PDD-NOS) or probable/suspected disorders that had not been officially diagnosed. Of those disorders listed above, the most commonly reported were Sensory Integration Processing Disorder (n = 100, 25.4%) and ADD/ADHD (n = 88, 22.4%), while few reported mental retardation (n = 36, 9.2%). Additional information regarding comorbid diagnoses as well as whether or not the child had a family history of autism or other mental-health disorders is provided in Table 13.

Table 13

Comorbid Diagnostic Information

Diagnosis	Frequency (%)
Closed-ended diagnoses	
ADD/ADHD	88 (22.4%)
Brain damage	8 (2.0%)
Mental Retardation	36 (9.2%)
Seizure Disorder	1 (0.3%)
Sensory Integration Processing Disorder	100 (25.4%)
Tuberous sclerosis	1 (0.3%)
Open-ended, other diagnoses (total)	74 (18.8%)
Affective Disorder (anxiety, depression, bipolar)	9 (2.3%)
Central Auditory Processing Disorder	3 (0.8%)
Cerebral palsy	3 (0.8%)
Dyspraxia/apraxia	6 (1.5%)
Epilepsy	1 (0.3%)
Hyperlexia	3 (0.8%)
Kabuki Syndrome	1 (0.3%)
Learning disabled	3 (0.8%)
Neurological/brain disorder	6 (1.5%)
Obsessive Compulsive Disorder	15 (3.8%)
Oppositional Defiant Disorder	4 (1.0%)

Schizophrenia	1 (0.3%)
Tic disorder	1 (0.3%)
Triple X Syndrome	1 (0.3%)
Multiple other diagnoses (e.g., depression and OCD)	11 (2.8%)
Other	6 (1.5%)
Family history of autism or other mental-health disorders	
No	218 (57.8%)
Yes	159 (42.2%)

Early characteristics. Several characteristics were indicated by more than 60% of the sample as those first noticed as being different in their children, the most common of which was language delay (*n* = 321, 84.7%), detected at an average age of 1.8 years. The 2 characteristics that were least frequently reported, "failure to attach to caregiver" and "slowness in meeting motor milestones," were those detected at the youngest average ages, 1.4 years and 1.2 years, respectively. More information regarding characteristics noticed and average age of detection is provided in Table 14. Eighty-seven participants (23%) reported other or additional characteristics that they first perceived as being different in their children in open-ended format, which can be seen in Table 15. Because of the diversity and infrequency of common responses within this variable, means and standard deviations were not computed; however, the age range for noticing other early characteristics was 0 to 9.33 years, with the bulk of participants in this group (*n* = 71, 81.6%) detecting such differences within their children's first 2 years.

Table 14

*Ages in Years at Which Early Characteristics Were First Noted**

Characteristic	Mean	Median	*SD*	Range	*n* (%)
Slowness in meeting motor milestones (e.g., crawling)	1.2	1.0	1.5	0 to 16	143 (37.7%)
Failure to attach to caregiver	1.4	1.0	1.4	0 to 9.2	91 (24%)
Failure to use/respond to gestures (e.g., pointing)	**1.6**	**1.5**	.9	0 to 9.2	**248 (65.4%)**
Lack of responsiveness (e.g., to name, suggestions)	**1.7**	**1.5**	1.0	.1 to 9.2	**273 (72%)**
Lack of social smiling	1.7	1.5	1.8	0 to 18	167 (44.1%)
Language delay	**1.8**	**1.5**	.9	0 to 8.8	**321 (84.7%)**
Lack of eye contact	**1.9**	**1.5**	1.3	0 to 8.8	**280 (73.9%)**
Unusual interaction with or attachment to objects	**2.0**	**1.9**	1.4	.1 to 10	**251 (66.2%)**
Lack of imaginative or pretend play	**2.1**	**2.0**	1.0	.2 to 9	**263 (69.4%)**
Unusual physical behaviors (e.g., hand-flapping, rocking)	**2.2**	**2.0**	1.9	0 to 22	**245 (64.6%)**
Not playing with other children	**2.2**	**2.0**	1.1	0 to 9.1	**294 (77.6%)**

* Bolded numbers indicate those for which more than 60% of the sample indicated noticing that characteristic.

Table 15

*Open-ended Responses to Other Characteristics First Noticed**

Characteristic	Frequency (%)
Aggressive behavior	2 (0.5%)
Behavioral difficulties	3 (0.8%)
Clumsiness	1 (0.3%)
Excessive crying	1 (0.3%)
Different (“gut feeling”)	1 (0.3%)
Dislike of previously enjoyed activities	1 (0.3%)
Gastrointestinal problems (reflux, vomiting, diarrhea)	3 (0.8%)
General loss of interest in activities	1 (0.3%)
Head-banging	2 (0.5%)
Hyperactivity	1 (0.3%)
Hyperlexia	2 (0.5%)
Issues with food/feeding	3 (0.8%)
Language loss	10 (2.6%)
Lining up of objects	4 (1.1%)
Makes odd noises/sounds	4 (1.1%)
Negative affect (“bad mood”)	1 (0.3%)
No fear of dangerous situations	1 (0.3%)
Non-responsiveness	1 (0.3%)
Obsessions	5 (1.3%)

Overly attached to caregiver	2 (0.5%)
Overly imaginative	1 (0.3%)
Overly intelligent	1 (0.3%)
Recurrent illnesses/sickly	1 (0.3%)
Reliance on routines	6 (1.6%)
Seemingly deaf	2 (0.5%)
Seemingly in "own world"	4 (1.1%)
Self-injurious behavior	1 (0.3%)
Sensory issues	6 (1.6%)
Skill regression	3 (0.8%)
Sleep disturbances	3 (0.8%)
Tantrums	2 (0.5%)
Toe walking	1 (0.3%)
Toileting issues	2 (0.5%)
Unusual/excessive fears	2 (0.5%)
Multiple other characteristics (e.g., loss of language + toileting issues)	6 (1.6%)

* Age ranges for these characteristics were from 0 to 9.3 years.

Hypothesis-testing. The prediction that participants who reported larger incomes and greater education will also report noticing early characteristics of autism in their children at younger ages (hypothesis 1) was not supported. Thus, regardless of income and level of educational attainment, participants noticed early characteristics of autism in their children at the same average ages. Pearson correlations between these variables can be seen in Table 16.

Table 16

Correlations Between Participant Income, Education, and Ages of Early Characteristics

Variable	Parent Educational Level	Approximate Family Income
Parent educational level (*n* = 373)	1	.422*
Approximate family income (*n* = 359)	.422*	1
Lack of eye contact age (*n* = 276)	.040	.098
Lack of social smiling age (*n* = 166)	-.059	.005
Failure to attach to caregiver age (*n* = 90)	-.067	.171
Slowness in meeting motor milestones age (*n* = 141)	-.059	.017
Lack of responsiveness age (*n* = 271)	-.103	-.056
Failure to use/respond to gestures age (*n* = 245)	-.047	-.056
Language delay age (*n* = 315)	-.103	-.015
Unusual physical behaviors age (*n* = 241)	-.018	.014
Unusual interaction with/attachment to objects age (*n* = 248)	-.041	-.015
Lack of imaginative/pretend play age (*n* = 260)	-.009	.002
Not playing with other children age (*n* = 290)	.006	-.018

* $p < .01$, 2-tailed

One-way analyses of variance were computed to test the notion that parents who reported a congenital onset of autism in their children would notice characteristics of the disorder at earlier ages relative to parents who reported a regressive onset (hypothesis 2). While parents who reported a congenital onset noted all 11 characteristics at younger average ages relative to parents reporting a regressive onset, significant differences between groups were noted for only 4 of the 11 early symptoms: age for failure to attach to caregiver, $F(1, 71) = 10.779$, $p = .002$; age for lack of responsiveness, $F(1, 224) = 8.681$, $p = .004$; age for failure to use or respond to gestures, $F(1, 198) = 7.797$, $p = .006$; and age for unusual interaction with or attachment to objects, $F(1, 199) = 5.021$, $p = .026$. Further results may be seen in Tables 17 and 18.

Table 17

One-Way Analyses of Variance for Effects of Congenital or Regressive Onset on Ages at which Early Characteristics Were Noted

Variable and Source	*df*	*SS*	*MS*	*F*
Lack of eye contact				
Between groups	1	1.914	1.914	1.279
Within groups	226	338.282	1.497	
Lack of social smiling				
Between groups	1	5.216E-02	5.216E-02	.016
Within groups	132	420.745	3.187	
Failure to attach to caregiver				
Between groups	1	8.496	8.496	10.779**
Within groups	71	55.963	.788	
Slow to meet motor milestones				
Between groups	1	2.408	2.408	.890
Within groups	110	297.681	2.706	
Lack of responsiveness				
Between groups	1	8.008	8.008	8.681**
Within groups	224	206.637	.922	
Failure to use/respond to gestures				
Between groups	1	4.510	4.510	7.797**
Within groups	198	114.520	.578	

Language delay				
Between groups	1	1.173	1.173	1.687
Within groups	255	177.272	.695	
Unusual physical behaviors				
Between groups	1	10.698	10.698	2.934
Within groups	199	725.686	3.647	
Unusual interaction with or attachment to objects				
Between groups	1	6.862	6.862	5.021*
Within groups	199	271.991	1.367	
Lack of imaginative/pretend play				
Between groups	1	.194	.194	.277
Within groups	210	147.203	.701	
Not playing with other children				
Between groups	1	6.032E-02	6.032E-02	.061
Within groups	235	233.547	.994	

* $p < .05$, ** $p < .01$

Table 18

Means and Standard Deviations for Ages at which Early Characteristics Were Noted per Type of Onset

Variable	Congenital Onset		Regressive Onset	
	M	*SD*	*M*	*SD*
Lack of eye contact	1.7	1.5	1.9	1.0
Lack of social smiling	1.7	2.5	1.8	0.8
Failure to attach to caregiver	0.9	0.6	1.6	1.1
Slow to meet motor milestones	1.1	2.0	1.4	0.9
Lack of responsiveness	1.5	0.9	1.9	1.0
Failure to use/respond to gestures	1.4	0.8	1.7	0.7
Language delay	1.7	0.9	1.8	0.8
Unusual physical behaviors	2.0	1.5	2.4	2.2
Unusual interaction with or attachment to objects	1.8	1.0	2.2	1.3
Lack of imaginative/pretend play	2.1	0.9	2.1	0.8
Not playing with other children	2.2	0.9	2.2	1.1

A chi-square analysis was performed to assess whether there were differences in participants' beliefs about causes of autism (external versus genetic) relative to the type of autism development (congenital versus regressive) witnessed in their children (hypothesis 3). Although several categories of causal mechanisms were generated, this analysis only included purely external and purely genetic beliefs, which were the two most commonly reported by parents and collectively encompassed almost 43% of all responses to this query. Participants who indicated that their children always exhibited autistic characteristics were significantly more likely to believe autism was a genetic disorder, whereas those whose children exhibited a developmental-regressive onset more often believed it was caused by some external trigger, $\chi^2(1) = 54.899$, $p < .001$. Results are provided in Table 19.

Table 19

Frequencies of Beliefs About Genetic and External Causes of Autism Per Congenital and Regressive Onsets

Onset	Beliefs Regarding Causes		$\chi^2(1)$	*p*
	External	Genetic		
	(*n* = 53)	(*n* = 76)		
Congenital (*n* = 60)	4	56	54.899	<.001
Regressive (*n* = 69)	49	20		

Chi-square analyses were conducted to determine whether (a) participants more often reported that they got information about autism from the informal resources of

websites/e-mail listservs when they believed autism was caused by some external mechanism and (b) participants more often reported that they got information about autism from the professional resource of scientific journals when they believed autism had a strictly genetic origin (hypothesis 4). There were no significant differences between groups believing in an external mechanism versus genetics in terms of accessing (a) websites/e-mail listservs, $\chi^2(1) = .009$, $p = 1.000$, or (b) scientific journals, $\chi^2(1) = .148$, $p = .730$. Results are provided in Table 20.

Table 20

Frequencies of Accessing Different Informational Resources Per Beliefs About Cause

Belief About Cause	Websites/E-mail listservs		$\chi^2(1)$	*p*
	No	Yes		
	(n = 17)	(n = 120)		
External mechanism			.009	1.000
(n = 55)	7	48		
Genetics				
(n = 82)	10	72		
	Scientific Journals			
	No	Yes		
	(n = 70)	(n = 67)		
External mechanism			.148	.730
(n = 55)	27	28		
Genetics				
(n = 82)	43	39		

A chi-square analysis was also performed to determine whether participants were more likely to report that their children presented with comorbid diagnoses when they also exhibited a congenital-autism onset (hypothesis 5). There were no significant differences between groups reporting congenital versus regressive onset relative to presence or absence of comorbidity, $\chi^2(1) = 2.445$, $p = .134$. Results are provided in Table 21.

Table 21

Frequencies of Presence vs. Absence of Comorbidity Per Type of Onset

Type of Onset	Presence vs. Absence of Comorbidity		$\chi^2(1)$	p
	Absence (n =149)	Presence (n = 152)		
Congenital (n = 145)	65	80	2.445	.134
Regressive (n = 156)	84	72		

Independent samples t-tests were employed to test (a) if participants who reported comorbid diagnoses in their children would also notice quantitatively more early characteristics of autism (hypothesis 6), (b) if the presence of a family history of autism or other mental-health disorders rendered families more attuned to autistic symptoms at earlier ages in their children (hypothesis 7) and (c) if the presence of a family history of autism or other mental-health disorders rendered families more attuned to a greater quantity of early characteristics in their children (hypothesis 8). Bonferoni adjustments to *p*-values were included to guard against spurious findings. In each case, the hypothesis

was not supported. There were no significant differences in (a) the number of early-autism characteristics noticed between parents who did and did not report comorbid diagnoses in their children, $t(368.692) = -.181$, $p = .857$; (b) the ages at which parents who did and did not report a family history of autism or other mental-health disorders identified early concerns (see Table 22), or (c) the quantity of early-autism characteristics noticed between parents who did and did not report a family history of autism or other mental-health disorders, $t(375) = -.846$, $p = .398$.

Table 22

Group Differences in Ages at Which Early Characteristics Were Noted Between Families Reporting and Not Reporting a Family History of Autism/Mental-Health Disorders

Variable	No Family History		Family History		*t*(*df*)*
	M	*SD*	*M*	*SD*	
Lack of eye contact	1.81	1.30	1.92	1.36	-.677 (277)
Lack of social smiling	1.80	2.03	1.64	1.29	.579(164)
Failure to attach to caregiver	1.37	1.18	1.41	1.68	-.134(88)
Slow to meet motor milestones	1.37	1.84	.98	.79	1.522(141)
Lack of responsiveness	1.63	.76	1.75	1.30	-.907(182)
Failure to use/respond to gestures	1.57	.69	1.62	1.10	-.396(178)
Language delay	1.75	.86	1.81	1.03	-.569(318)
Unusual physical behaviors	2.32	2.30	2.06	1.11	1.068(243)
Unusual interaction with/ attachment to objects	1.98	1.22	2.07	1.49	-.518(248)
Lack of imaginative/ pretend play	2.14	.82	2.10	1.11	.297(260)
Not playing with other					

children	2.12	.89	2.36	1.25	1.776(211)

*$p > .05$

Stepwise multiple regression analyses were conducted with the ages at which parents reported noticing each of the 11 early-autism characteristics, with ages serving as the criterion variables and (a) type of autism onset (congenital versus regressive), (b) presence versus absence of comorbidity in children, and (c) presence versus absence of a family history of autism or other mental-health disorders as the predictor variables. Type of autistic onset alone significantly predicted the ages at which parents noticed both failure to attach to caregiver, β = -.363, t = -3.283, p = .002, R^2 = .132, and lack of responsiveness, β = -.193, t = -2.946, p = .004, R^2 = .037. In both instances, parents who indicated that their children always exhibited signs of autism (congenital) reported noticing these characteristics at earlier ages relative to parents who indicated that their children did not always exhibit autistic symptoms (regressive).

Presence versus absence of comorbidity significantly predicted the ages at which parents noticed (a) language delay, β = .193, t = 3.134, p = .002, R^2 = .037; (b) lack of imaginative or pretend play, β = .209, t = 3.102, p = .002, R^2 = .044; and (c) not playing with other children, β = .277, t = 4.420, p < .0001, R^2 = .077. In each of these cases, parents whose children presented with comorbid diagnoses reported noticing these characteristics at later ages relative to parents whose children did not have additional diagnoses.

Type of autistic onset and presence versus absence of comorbidity in children each significantly predicted the age at which parents noticed a failure to use or respond to gestures, β = -1.95, t = -2.792, p = .006, R^2 = .038, and β = .151, t = 2.199, p = .031, ΔR^2 = .023, respectively. However, presence versus absence of a family history of mental

health disorders did not significantly predict the age at which parents noticed a failure to use or respond to gestures, β = -.011, t = -.15, p > .05, ΔR^2 = .000. Combined, these variables accounted for 6.1% of the total variance in age at which parents noticed a failure to use or respond to gestures. Parents whose children presented with a congenital onset noticed a failure to use or respond to gestures in their children at earlier ages relative to parents whose children developed autism in a regressive fashion. However, parents whose children experienced comorbidity noticed their children's failure to use or respond to gestures at later ages compared with parents whose children did not have additional diagnoses.

Presence versus absence of comorbidity in children and type of autistic onset each significantly predicted the age at which parents noticed their children's unusual interactions with/attachment to objects, β = .202, t = 2.914, p = .004, R^2 = .041, and β = -.166, t = -2.420 p = .016, ΔR^2 = .028, respectively. However, presence versus absence of a family history of mental health disorders did not significantly predict the age at which parents noticed their children's unusual interaction with/attachment to objects, β = .036, t = .507, p > .05, ΔR^2 = .001. The combined variables accounted for 7 % of the variance in age at which parents noticed their children's unusual interactions with/attachment to objects. Parents whose children presented with comorbidity noticed unusual interactions with/attachment to objects at later ages relative to parents whose children did not have additional diagnoses. Parents whose children experienced a congenital onset noticed unusual interactions with/attachment to objects at earlier ages compared with parents whose children presented with a regressive onset.

Type of autism onset, presence versus absence of comorbidity, and a family history of mental health disorders did not account for a significant proportion of the variance in ages of detecting (a) lack of eye contact, (b) lack of social smiling, (c) slowness in meeting motor milestones, or (d) unusual physical behaviors.

Discussion

The purpose of this investigation was to (a) better understand how parents view the development of autism in their children, specifically early characteristics of the disorder; (b) document potential commonalities within parents' reports of the emergence of autistic symptoms in their children among a large sample; and (c) report the frequencies of and potential impact upon early characteristics of regressive tendencies, comorbidity, and family history of mental-health disorders. It was further deemed appropriate to consider parents' beliefs about causes of autism and how this factor interplayed with the way in which autism developed in their children.

Demographic Information on Children

Almost 400 parents and other caregivers of children experiencing autism-spectrum disorders from around the globe provided rich, descriptive information about their children and families. The majority of children described were male, with a ratio of 4 to 5 males for 1 female, which is in line with the current notion of autism's expression across gender. Children's average current age was 8.5 years, with females being older than males across autism-spectrum diagnoses. Similarly, girls were more likely to be diagnosed at later ages than were boys across diagnoses. It seems unlikely that girls would, on the whole, exhibit symptoms of autism at later ages than would boys; however, it does beg the question of how severity of autism may impact the detectability of early characteristics. Degree of autism severity depends upon both the number of unusual or problematic behaviors that one expresses and the extent to which those characteristics impede salient-skill performance (e.g., toileting, self-help, language), thus the concept is

based upon *characteristics*. However, the current study did not seek information regarding degree of severity, so it is impossible to say whether boys were presenting with more moderate to severe forms of the disorder relative to females, thus prompting parents of affected boys to seek professional attention at earlier ages. Perhaps girls were diagnosed later simply because autism is a less frequent condition for girls and so physicians and other diagnosticians were more reticent to affirm the diagnosis for a female.

Children presenting with autism and PDD-NOS received these diagnoses at 3.5 years and 4.5 years, respectively. The fact that PDD-NOS was reportedly diagnosed at 1 year later (on average) relative to autism may seem unusual, as some professionals who are hesitant to diagnose autism may provide an initial diagnosis of PDD-NOS when the child is young and a subsequent diagnosis as he/she gets older and they are more certain about his/her symptoms meeting autism criteria. The *DSM-IV* distinguishes PDD-NOS from autism based on the (a) unusual presentation of characteristics that do not quite match up with those necessary for an autism diagnosis and/or (b) initial exhibition of autism characteristics at ages later than 3 years. Considering this, it is not surprising that some children receive a PDD-NOS diagnosis at later ages relative to those receiving an autism diagnosis, as the search for the most appropriate category is lengthier. However, children with Asperger's syndrome were diagnosed at much later ages relative to these 2 groups, at an average age of 7.5 years. This suggests that Asperger's syndrome has become more frequently diagnosed in recent years; conceivably, those children who did not exactly fit the criteria for autism when they were aged 3 and 4 (and who may have

had an initial diagnosis of PDD-NOS) may be receiving this diagnosis at later ages as specialists become more aware of it and deem it more appropriate.

With regard to comorbidity, about half of the sample indicated that their children had one or more additional diagnoses outside of the autism spectrum. More than 25% of parents indicated that their children had a further diagnosis of Sensory Integration Processing Disorder (SI) and more than 20% indicated that their children were also diagnosed with ADD/ADHD. This is an intriguing finding and begs the question of why these diagnoses so commonly occurred among the present sample. It may be that whether or not a child receives one of these 2 additional diagnoses has more to do with the type of professional or team making the diagnosis. Teams that include occupational therapists, who tend to be sensitive to sensory-issue aversions, may be more likely to propose SI as a secondary diagnosis.

Characteristics associated with SI and ADD/ADHD (e.g., aversions to sounds or certain textures for SI and hyperactivity for ADHD) are typically not similar to those associated with autism-spectrum disorders per diagnostic criteria, thus unnecessary overlap in diagnoses, which might occur with comorbid autism and OCD, does not seem likely. However, there appears to be an increasing trend for these disorders to coexist, whether it is autism and SI or ADD and SI, which may relate to the fact that all have roots in the child's nervous-system processing of information. Historically, ADD/ADHD diagnoses occur at later ages relative to autism-spectrum diagnoses, largely because inattentiveness and distractibility become more apparent when children reach school age and must participate in classroom settings that may be more restrictive than those to

which they are accustomed. So it is presumed that children are receiving autism diagnoses first and other behavioral diagnoses later. Yet in 6 cases, parents reported sensory issues and in 1 instance, hyperactivity, as one of the early characteristics that they first noted as being different in their children. More research is warranted in this arena, particularly to delineate whether or not these early characteristics (albeit associated with other disorders) are indicative of autism risk among infants and toddlers.

One interesting finding that may relate to the prevalence of comorbid SI and ADD/ADHD diagnoses in the current sample is the marked absence of an additional diagnosis of mental retardation (MR), with only 9% reporting. This, to our knowledge, is the lowest number of co-occurring autism and MR in the reported literature, as the most modern works continue to describe the comorbidity of MR as occurring in 75% to 80% of affected individuals. It may be that SI and ADD/ADHD are replacing this traditional secondary diagnosis as we become more specific about categorizing groups of anomalous behaviors. However, it is also plausible that parents may not be reporting an MR diagnosis because they are unaware that their children meet the criteria for MR. Nowadays, the diagnosis of autism alone is enough to command appropriate therapeutic and educational services for affected children, so professionals may find it unnecessary to make a formal diagnosis of MR known to parents, as it tends to carry more negative connotations that can be difficult for parents to acknowledge. Nevertheless, this study sought parents' perspectives on issues related to their children, and findings indicated that their endorsement of MR was low.

Early Characteristics

Participants provided rich information regarding the early symptoms they first noticed as being different in their children. Overall, the very young ages (from 1.2 to 2.2 years on average) at which they detected oddities indicates a time lag between symptom presentation and diagnosis of 1.3 to 3.3 years—a lengthy wait for parents trying to figure out what may be affecting their children. More than 60% of the entire sample indicated that they noticed 8 of the 11 characteristics specifically queried, with those noticed at older ages (e.g., 2.2 years) being reported more frequently than those noticed at younger ages (e.g., 1.2 years). This 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. With the exceptions of lack of eye contact, lack of social smiling, and lack of imaginative or pretend play, most parents seemed to notice the absence of typical characteristics/presence of unusual characteristics at ages that were developmentally appropriate to notice such differences. However, the age ranges of detection were odd in many instances, with some parents reporting a given characteristic at age 0 (presumably from birth) and others not reporting an appearance of that same characteristic until the teen years (i.e., ages 16, 18, or 22). It is unclear as to whether or not these cases represented participant typos (e.g., indicating 18 months in the column outlined for years) or if these behaviors actually presented much later in these children following the onset of adolescence.

There were a total of 35 additional characteristics or combination of characteristics that parents reported in open-ended format as initially causing them

concern. Almost all are consistent with symptoms queried either in other studies of the presentation of early characteristics of autism (e.g., Young, Brewer, & Pattison [in press]) or the comorbidity literature previously cited. Given the somewhat qualitative nature of this particular question, it would be interesting to subsequently distribute a closed-ended questionnaire containing these characteristics to better asses their frequencies among a large audience.

Interpretations of Hypotheses

The prediction that parent income and education levels would be related to the ages at which parents noticed early characteristics was not supported. The majority of the sample came from upper-socioeconomic brackets, and the average length of educational experience was 15 years (equivalent to a junior in college); however, the actual ranges within these variables is noteworthy and likely would have illustrated a relationship had there been one. This suggests that autism characteristics are deemed so atypical that most any parent, regardless of his or her income and/or educational level, would pick up on such behaviors early in his or her child's life. However, it might be that parents' connectedness to autism-support groups/organizations, as was the case with this sample, relates to their early awareness of autistic symptoms; thus, a difference may exist between the ages at which parents notice early characteristics when they are or are not affiliated with such organizations.

Of the 11 early characteristics, only 4 were noted by parents whose children exhibited congenital autism as appearing at significantly earlier ages compared with parents whose children experienced a regressive onset. Three of these 4—failure to attach

to caregiver (1.4 years), failure to use/respond to gestures (1.6 years), and lack of responsiveness (1.7 years)—were among the top 4 characteristics noticed at the youngest ages, with unusual interaction with/attachment to objects appearing at a later average age (2 years). It is puzzling that a lack of characteristics developmentally appropriate even for infants, such as eye contact and social smiling, were not reported at significantly younger ages among the congenital group. Parents who indicated a congenital onset of autism in their children likely noticed symptoms within their children's first several months of life, otherwise they may not be as inclined to think their children experienced autism from birth. However, it may be that the symptoms they did notice were not necessarily those that were specifically queried.

As predicted, parents who reported a congenital development of autism in their children tended to attribute the disorder to a genetic cause, whereas those who reported a regressive onset attributed autism to some external mechanism. This makes sense. If anomalous characteristics are present from birth or very early on in life, there seems to be little room for implicating some outside force as dramatically altering behaviors (and only 4 individuals fell into the congenital onset/external-trigger belief category). On the other hand, when a child appears to be developing normally and suddenly exhibits marked changes in behavior, particularly following a specific event (e.g., vaccination), it is easy to see how parents' explanations follow a cause-and-effect model where some external force must be at work.

Where parents got their information about autism (webpages/e-mail listservs and/or scientific journals) did not appear related to their beliefs about autism's etiology as

genetic or triggered by some external mechanism. Participants could select both resources (as well as others that were not considered in this investigation), and it was apparent that they relied on a variety of outlets for garnering information about autism. Websites/e-mail listservs were much more frequently reported as being accessed relative to scientific journals, probably because they are more readily available to lay populations.

It was believed that participants would more often report comorbid diagnoses in their children if they had congenital autism, simply because problems that are apparent so early in life may be the expressed-symptomatic culmination of 2 or more disorders exacerbating the presentation of 1 or both. However, this was not the case, and those experiencing congenital autism were comorbid with about the same frequency as were those experiencing regressive autism. Additional diagnoses, then, seem part and partial of an autism-spectrum diagnosis in approximately 50% of cases. It was also believed that participants who reported comorbid diagnoses in their children would notice quantitatively more early characteristics of autism, for a reason similar to the one cited above: that the expressed-symptomatic culmination of 2 or more disorders would yield a higher quantity of unusual behaviors. Again, this was not the case. However, in light of the 2 most commonly reported additional diagnoses—SI and ADD/ADHD—which are diagnosed at later average ages than autism is diagnosed, this is not surprising. If autism characteristics come about first, during the first 2 years of life, then behaviors that warrant a second diagnosis down the road probably either have not yet appeared or have not yet appeared to the degree that they color early-autism symptoms much differently.

Having a family history of autism or other mental-health disorders did not affect the quantity of early characteristics that parents noticed or the ages at which such symptoms were detected. It was thought that if family members were aware of oddities affiliated with diagnoses of other family members that they would be more sensitive to potential differences in their own children. This evidence to the contrary, though, further bolsters the findings presented throughout this work that autism characteristics consistently seem to be appearing at least between 12 and 24 months of age, regardless of other factors that may be thought to affect parents' sensitivities to their presentation. However, it is conceivable that participating families underreported their family-history of mental-health disorders, especially given that (a) they had the opportunity to indicate even distant relatives and (b) mothers were the ones most often completing the questionnaire and may have selectively excluded their own mental-health issues. Given the size of this sample, it was expected that the rates of affective disorders among relatives of individuals with autism would be high, based upon the previously cited literature on this topic, yet rates did not differ from that within the general population.

The predictor variable of type of autism onset significantly predicted the age at which parents noted both their children's failure to attach to a caregiver and lack of responsiveness, with parents whose children had congenital autism noticing them earlier than those whose children had regressive autism. Both of these characteristics are salient and basic social skills that many parents expect to see within the first year of life, and perhaps within the first 6 months. Thus, the absence of these characteristics, and perhaps others not specifically queried, may be largely responsible for *why* these parents believed

their children always had autism. The opposite effect was observed with the predictor variable of presence versus absence of comorbidity and the ages at which parents noticed language delay, lack of imaginative or pretend play, and not playing with other children. Parents whose children had comorbid diagnoses were likely to notice these characteristics at later ages compared with parents whose children were not comorbid. This was an unexpected finding but interesting in the sense that all 3 of these behaviors are social skills that would not be expected of very young children, particularly imaginative/pretend play and playing with other children. Developmentally appropriate play for toddlers is parallel play, in which they play alongside peers but not cooperatively with them. Regardless of type of autism onset, the average age at which parents indicated the absence of these skills was markedly lower than what would be expected even of typically developing children (between ages 3 and 4), much less those who had already been displaying socially anomalous behaviors. However, that the parents of children with additional diagnoses, compared with those of children without comorbidity, reported noticing differences in these skills at later ages may indicate their slightly more realistic expectations as to when it is appropriate for these behaviors to emerge.

An interesting trend occurred for the predictor variables of age at which parents noticed a failure to use or respond to gestures and age at which parents noticed their children's unusual interactions with/attachment to objects. In each of these cases, parents detected anomalies in these behaviors at (a) earlier ages when they described their children as having a congenital-autism onset and (b) later ages when their children experienced comorbidity. With the age at which parents noticed their children's failure to

use or respond to gestures, more of the variance was explained by type of onset, while in the age at which parents noticed their children's unusual interactions with/attachment to objects, more was explained by presence versus absence of comorbidity. While it was predicted that parents would notice these characteristics at earlier ages when they described a congenital onset, the same prediction in terms of comorbidity did not hold true but matches results found with the ages at which parents noticed language delay, lack of imaginative or pretend play, and not playing with other children. It is possible that when children have additional diagnoses, there are more physical, behavioral, emotional, and/or intellectual challenges with which parents are concerned so that they may be absorbed with the development and mastery of very basic skills and therefore not as attuned to those initially viewed as less critical. For example, many parents indicated that their children had some type of comorbid feeding disorder that typically began early in life. If parents are focused on getting food into their children's bodies, then the fact that their children are not pointing or waving good-bye may take a backseat to worries about their feeding issues. In some cases, parents may feel that the mastery of primary skills (e.g., eating, walking) plays a part in the development of secondary skills (e.g., imaginative and social play) so that they logically do not expect their children to be displaying certain actions before the development of others. Perhaps only after some primary skills have improved or are resolved do they then begin to notice other anomalous or absent behaviors.

Limitations

Because the questionnaire was posted on the Internet, it was only accessible to those individuals who had both computer and Internet availability; and for this reason, it was expected that most participants would have at least a high-school education (some computer familiarity) and come from middle to upper socioeconomic backgrounds (Newburger, 2001; Simsek & Veiga, 2000). At the time of the 2000 U.S. census, 51% of households had at least one computer and 42% of these homes had Internet access (Newburger, 2001). These figures increased when a school-aged child (6 to 17 years old) lived in the home to 67% for computer availability and 53% for Internet access. However, computer and Internet availability in the home varied across races, with 56% of White (non-Hispanic) homes, 33% of Black homes, 65% of Asian homes, and 34% of Hispanic (and other) homes reporting computer access and 46% of White (non-Hispanic) homes, 24% of Black homes, 56% of Asian homes, and 24% of Hispanic (and other) homes reporting Internet access (Newburger, 2001). Therefore, the media through which the questionnaire was presented may have been exclusionary, more so for those in Black and Hispanic homes, which could help explain the disproportionate number of White participants. However, the aforementioned percentages of computer/Internet access by race are not comparable, by far, with the racial distribution within the present study, which begs the question of the frequency of autism's expression among various racial and ethnic groups. The present sample under-represented Black, Hispanic, and Asian families, and it also under-represented lower-income homes. However, it is *not* suggested

that the racial and economic samples who responded to this questionnaire are an epidemiological representation of children with autism.

The questionnaire was originally intended for advertisement only within the Commonwealth of Virginia. When the decision was made, however, to publicize it internationally, no changes were made in its language or answer choices to reflect different cultural perceptions. For example, approximate family income was based solely on U.S. dollars, without the option of selecting country-appropriate currencies. This may have impacted, in some cases, the accuracy of participants' reports on this matter or even discouraged their provision of such information. Moreover, one participant, in an open-ended response to the other diagnoses that her child received, indicated that PDD-NOS was not considered a disorder separate from autism in the United Kingdom but rather PDD was the primary diagnosis that a child would receive and autism or Asperger's Syndrome would be the secondary diagnosis (items were recoded in cases where this occurred). Clearly, even the format of this diagnosis is culture specific.

There were a few items of interest that would have enhanced the questionnaire and, perhaps, helped to explain further some of the findings, one of which is perceived degree of autism severity. As noted previously, boys were consistently diagnosed at earlier ages relative to girls, yet it is unclear as to whether or not their symptomatic presentation was more dramatic, which may have prompted parents to seek professional help for them at earlier ages. Additionally, parents of those more severely affected may have reported (a) characteristics at earlier ages, (b) qualitatively different characteristics, and/or (c) more comorbidity in their children relative to parents whose children were

mildly affected. Additionally, the ages at which parents noted early characteristics sometimes varied significantly, with some expecting typical skills to emerge at younger ages than is appropriate to anticipate and others noticing autism traits at markedly later ages than what is commonly reported for affected children. It would have been helpful to know at what ages parents expected certain behaviors and skills to emerge among typically developing children to get a better understanding of their comparative bases.

Finally, no identifiable information was obtained from participants, so it was impossible to contact them for clarification of responses, which would have been particularly helpful in interpreting some of their answers to qualitative questions. While the decision to provide anonymity (as opposed to just confidentiality) may have encouraged participants to cooperate and be more open about their families' experiences, it may be helpful to get IRB approval for obtaining such information so that unclear data can be explained and incorporated into analyses.

Implications for Future Research

Results from this study are valuable in that they revealed information yielded from a large, international sample, thus corroborating results from other studies focusing on similar autism constructs while also offering unique and novel information to the autism literature. However, as stated previously, minority groups were under-represented in this work, and it is important to specifically target families of different races who experience autism so as to garner more pieces of the autism puzzle and be able to create programs and services that sensitively respond to the needs of a variety of peoples. Perhaps this same or a similar questionnaire could be presented to multicultural groups

but distributed through (a) supportive organizations aimed at enhancing autism awareness among ethnic minorities and (b) a more traditional venue (e.g., mailed-out, paper and pencil questionnaire).

The combination of both quantitative and qualitative techniques, while challenging at times, makes for the collection of more accurate data, as participants have the opportunity to share exactly what they mean and are not consistently restricted to closed-ended options that may not accurately reflect their realities. Moreover, qualitative measures provide an opportunity for the researcher to learn something that he or she may have never considered about his or her population of interest. It further allows those groups studied the chance to reveal any and all information they may want researchers to know about their situations with the hope that it will subsequently affect professional practices and policies to the benefit their families. It is not necessary for such methods to be conducted with large samples; in fact, most qualitative studies aimed at studying the intensity of a given phenomenon employ very few participants, sometimes 20 or less. Their merit is often overlooked, however, and many quantitative works would be markedly improved had their constructs and measures been born of results yielded through qualitative methodologies.

The means of using the computer and Internet as media through which to both advertise the study and collect data, again, were not without challenges and limitations. Given the speed of technological advances and the increasingly complex capabilities of various webpage-building programs, it is predicted that conducting research in this manner will become easier and subsequently more popular. At the time the present study

was advertised, several other autism-related Internet studies were also discovered, as they tended to be publicized on websites through the same autism-related organizations. It is a fast and inexpensive means to collect information from a large audience and does not restrict researchers to the small sample sizes typically associated with the study of infrequent phenomena, as has often been the case with autism research.

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Appendices

Appendix A

Date

Dear _____:

My name is Robin Goin and I am a doctoral candidate in the Department of Psychology at Virginia Commonwealth University, and my advisor, Dr. Barbara Myers, is an associate professor in the same department. We are conducting a study on parents' perceptions of the development of their children with autism and have created a web-based questionnaire that is posted on the Internet for parents/caregivers to complete using the computer. It can be accessed by visiting: http://www.pubinfo.vcu.edu/autismfamily/home.htm. Please feel free to go to this site so you can preview the questionnaire. It asks for information concerning (a) demographics on child and caregiver, (b) daily life, (c) early characteristics of the disorder, (d) the process of getting a diagnosis, (e) use of treatment/therapeutic options, and (f) how the disorder has generally progressed in their children. Participation will be both voluntary and strictly anonymous, as names and other contact information will not be sought.

The purpose in our contacting you is to ask that you help us promote our study by posting the enclosed advertisement in your organization's next newsletter, webpage update, and/or e-mail distribution. After data has been collected and analyzed, we would like to share the collective results with participants and other interested parties. We will send you a summary of our findings to post in your next newsletter, webpage update, and/or e-mail distribution. If you have any questions about the study or the advertisement, please feel free to contact Dr. Myers or me at the closing address.

We truly appreciate your time and cooperation. Again, if you have any questions or concerns, please do not hesitate to contact us.

Sincerely,

_____
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_____
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Enclosure

Appendix B

PARENTAL PERCEPTIONS OF THE DEVELOPMENT OF AUTISM IN THEIR CHILDREN

Are you the parent or caregiver of a child with autism?
Your child may be of any age, from infancy through adulthood.
If so, please consider participating in Virginia Commonwealth University's study on parents' perceptions of the development of autism in their children!

http://www.pubinfo.vcu.edu/autismfamily/home.htm

We are interested in learning more about how caregivers view and manage autism in their children. You are an expert on your child and know the most about him or her; we want to hear your story about the development of autism in your child and how it has affected your family.

Your participation would consist of completing a questionnaire on the Internet that asks for information about what your child's daily life is like, early characteristics of the disorder, your experience in getting a diagnosis, what types of therapies you've heard of and used, and how the disorder has progressed in your child. This type of information can lead to a better understanding of the experiences of families of children with autism so that identification, diagnostic, support, and therapeutic services may be enhanced. While we also ask for some basic demographic information (e.g., age, gender, race), participation is strictly anonymous and we will have no means of identifying you.

Sample questions include:

- *How old was your child when he or she received a formal diagnosis in the autism spectrum?*

- *How satisfied were you with the **process** of getting an autism-spectrum diagnosis?*

  _____ *Extremely satisfied*
  _____ *Moderately satisfied*
  _____ *Extremely dissatisfied*

- *What is your child like as a person?*

- *What is it that you like and/or dislike about the treatments you are currently using?*

Please feel free to visit the questionnaire website at: http://www.pubinfo.vcu.edu/autismfamily/home.htm to learn more information on the study and view the questionnaire. Participation is strictly voluntary, and all of your

responses will be completely anonymous. If you have any questions or concerns, please contact Robin Goin, doctoral candidate in the Department of Psychology at VCU, at s2rpgoin@mail1.vcu.edu or Dr. Barbara Myers, associate professor in the Department of Psychology at VCU, at bmyers@vcu.edu or (804) 828-6752. Your cooperation is greatly appreciated!

Appendix C

Organizations Contacted and Reported Venues of Study Advertisement

Location and Organization Name	**Venue(s)** [1]
United States	
Autism Society of America (ASA)	
Alabama	
Autism Society of Alabama	MB
Etowah-Calhoun-Cherokee Chapter	
Northern Alabama Chapter	
Shoals Area Chapter	
Arizona	
Pima County Chapter of ASA	
Greater Phoenix Chapter	
Arkansas	
Arkansas Autism Society	
California	
Autism Society of California	
Central California Chapter	
Coachella Valley Chapter	
North San Diego County Chapter	
Greater Long Beach/South Bay Chapter	

[1] CM = chapter-meeting distribution; E = e-mail list distribution; M = mailing to organization members; MB = message board posting on website; N = newsletter advertisement; R = acknowledged receipt of advertisement but did not indicate means of advertising; W = website advertisement

Inland Empire Chapter	
Orange County Chapter	
San Diego County Chapter	R
San Francisco Bay Area Autism Society	
San Gabriel Valley Chapter	
Ventura County Autism Society	
Colorado	
ASA Colorado Chapter	N, W
Autism Society of Boulder County	
Western Slope Chapter	
Southeast Chapter	
Southwest Chapter	
Northeast Chapter	
Northwest Chapter	
Mountains Chapter	
Autism Society of the Pikes Peak Region	
Connecticut	
Autism Society of Connecticut	
Fairfield County Chapter	
Natchang Region Autism Society	
Northeastern Connecticut Chapter	
South Center Connecticut ASA	

Delaware	
Delaware Autism Society	E
District of Columbia	
District of Columbia Autism Society	
Florida	
Autism Society of Florida	
ASA of the Palm Beaches	
Autism Society of Marion County	
Broward County Chapter	R (possible N)
Emerald Coast Autism Society	
First Coast Chapter	
Greater Orlando Chapter	
Gulf Coast Chapter	
Manasota Autism Society	
Miami-Dade County Chapter	
South Florida ASA	
Southwest Florida ASA	
Volusia County Chapter	
Georgia	
Greater Georgia Chapter	
Northeast Georgia Chapter	
Hawaii	

Autism Society of Hawaii	MB
Idaho	
Autism Society of Treasure Valley	
Panhandle Autism Society	
Illinois	
Autism Society of Illinois	R
Autism Society of Kankakee Valley	CM
Autism Society of Southern Illinois	
Chicago/South Suburban Chapter	R
Chicago Southside Chapter	
Far West Suburban Illinois Chapter	
North Suburban Illinois Chapter	
Northeast Illinois Chapter	
Northwest Suburban Illinois Chapter	MB
Indiana	
Autism Society of Indiana	
Central Indiana Chapter	
East Central Indiana Chapter	
Elkhart Area Chapter	
Northwest Indiana Chapter	
South Central Indiana Chapter	N
Southwest Indiana Chapter	

Tippecanoe Chapter	
Iowa	
Autism Society of Iowa	
East Central Iowa Chapter	
The Quad Cities Chapter	
Siouxland Chapter	
Southwest Iowa Chapter	
Kansas	
Autism Society of Kansas	
Autism Society of Johnson County Kansas	
Autism Society of Shawnee County	
Kentucky	
Autism Society of Western Kentucky	
Bluegrass Chapter	CM, E, M, W
Kentuckiana Chapter	
Purchase Area Chapter	
Louisiana	
Louisiana State Autism Chapter	
Acadian Chapter	
Baton Rouge Chapter	
Bayou Chapter	
Greater New Orleans Chapter	

Northeast Louisiana Chapter	E, N
Northwest Louisiana Chapter	
Southwest Louisiana Chapter	
Maine	
Autism Society of Maine	
Maryland	
Anne Arundel County Chapter	N
Baltimore-Chesapeake Chapter	N
Frederick County Chapter	
Howard County Chapter	
Prince Georges Chapter	
Montgomery County Chapter	N, W
Washington County Chapter	CM, MB
Massachusetts	
Massachusetts Chapter	N
Michigan	
Autism Society of Michigan	
Kalamazoo/Battle Creek Chapter	
Lansing Chapter	
Macomb/St. Clair Chapter	E, N
Oakland County Chapter	
Wayne County Chapter	

Minnesota	
Autism Society of Minnesota	
Mississippi	
Autism Society of Mississippi Gulf Coast Chapter	
Missouri	
Central Missouri Chapter	
Western Missouri Chapter	
Nebraska	
Autism Society of Nebraska	
Nevada	
Northern Nevada Chapter	
New Hampshire	
Autism Society of New Hampshire	
New Jersey	
Middlesex Chapter	
Southern New Jersey Chapter	
Southwest New Jersey Chapter (PACT)	W
New Mexico	
Autism Society of New Mexico	E, N
New York	
Albany Chapter	CM
Broome-Tioga Chapter	

Bronx Chapter	
Fulton/Montgomery County	
Hudson Valley Chapter	
Manhattan Chapter	
Nassau/Suffolk Chapter	
Queens County Chapter	N
Westchester Chapter	
Western New York Chapter	
North Carolina	
North Carolina State Chapter	
Chapel Hill Autism Local Unit	
Ohio	
Autism Society of Ohio	
Autism Society of Greater Cincinnati	R
Autism Society of Northwestern Ohio	
Central Ohio Chapter	
Dayton Ohio Chapter	
Greater Cleveland Chapter	
North Central Ohio Chapter	
Tri-County Autism Chapter	
Oklahoma	
Central Oklahoma Chapter	

Oregon	
Autism Society of Oregon	
Pennsylvania	
Penn Sac	
Autism Society of Pittsburg	
Berks County Chapter	
Blair County Chapter	
Cambria Chapter	
Greater Harrisburg Area Chapter	
Greater Philadelphia Chapter	
Lehigh Valley Chapter	E, N
Midwestern Pennsylvania Chapter	
Northwest Pennsylvania Chapter	
South Central Pennsylvania Chapter	
West Central Pennsylvania Chapter	
Rhode Island	
Autism Society of Rhode Island	
South Carolina	
South Carolina Autism Society	CM, E
South Dakota	
Black Hills Autism Society	
Tennessee	

Autism Society of Southeast Tennessee	
East Tennessee Chapter	R
Memphis Chapter	CM, E
Middle Tennessee Chapter	MB, N
Texas	
Autism Society of Greater Austin	
Autism Society of Greater Tarrant County	
Brazoria County Chapter	
Collin County Chapter	
Denton County Autism Society	
East Texas Chapter	
San Antonio Chapter	
Southeast Texas Chapter	
Southwest Texas Chapter	
Texas Gulf Coast Chapter	
Utah	
Autism Society of Utah	
Virginia	
Central Virginia Chapter	
Fredericksburg Chapter	
Greater Roanoke Valley Chapter	
Northern Virginia Chapter	E, MB, W

Peninsula Chapter	N
South Central Virginia Chapter	
Tidewater Chapter	N
The Autism Program of Virginia	E
Virginia Autism Resource Center	
Parent Educational Advocacy Training Center	
Parents for Autistic Children's Education	
The Faison School for Autism	E, N
Vermont	
Autism Society of Vermont	
Washington	
Autism Society of Washington	W
West Virginia	
Hancock County Chapter	
Huntington Area Chapter	
North Central West Virginia Chapter	
South Central West Virginia Chapter	
Wisconsin	
Autism Society of Wisconsin	
Autism Society of the Fox Valley	
Autism Society of Southeastern Wisconsin, Inc.	
Central Wisconsin Chapter	

Chippewa Valley Autism Society	R
The Lakeshore Chapter	
Madison Area Chapter	N
Northeast Wisconsin Chapter	
Center for the Study of Autism	
Cure Autism Now	W
-Illinois Chapter	
-Mid-Atlantic Chapter	
-New Jersey Chapter	
-San Francisco Bay Area Chapter	
National Alliance for Autism Research	
Australia	
Autistic Society of New South Wales	
Autism Association Queensland	
-Gold Coast Region	
-Cairnst Peninsula Region	
-Rockhampton Region	
-Gin Gin Region	
Autism Tasmania	
Autism Victoria	N
Autism Association of Western Australia, Inc.	
Autism Association of South Australia	

Canada	
Autism Society Canada	
Autism Society of Alberta	
Autism Society of British Columbia	
Family and Friends Autism Association	
Autism Society Manitoba	
Autism Society New Brunswick	
Autism Society of Newfoundland and Labrador	
Autism Society of Nova Scotia	
Autism/PDD of Mainland Nova Scotia	
Autism Society Ontario	
-Brantford Chapter	
-Chatham-Kent Area Chapter	
-Orangeville and Area Chapter	
-Owen Sound Area Chapter	
-Halton Area Chapter	E, N
-Hamilton Area Chapter	
-Kingston and Area Chapter	
-Toronto Area Chapter	
-Niagara Region Chapter	
-North Bayand Area Chapter	
-Ottowa Area Chapter	R

-Region d'Ottowa Area Chapter	
-Peel Region, including Mississauga Chapter	R
-Peterborough and Area Chapter	
-Renfrew County and Area Chapter	
-Sarnia and Area Chapter	E, W
-Sault Ste. Marie and Area Chapter	
-Simcoe and Area Chapter	
-Sudbury and Area Chapter	
-Thunderbay and Area Chapter	
-Upper Canada Chapter	
-Kitchener-Waterloo Area Chapter	
-Guelph & Area Chapter	
-Sturgeon Falls and Area Chapter	
-Windsor, Essex County Area Chapter	
-York Region Chapter	
The Autism Society of Prince Edward Island	
Saskatoon Society for Autism	
England	
National Autistic Society	W
Ireland	
Irish Society for Autism	
Asperger Syndrome Association of Ireland	N, W

Parents and Professionals and Autism	
New Zealand	
Autistic Association of New Zealand	
-Northland Branch	
-Auckland Branch	
-Waikato Branch	CM, E, N
-Tauranga Branch	
-Hawkes Bay Branch	
-Taranaki Branch	
-Gisborne Branch	
-Wanganui Branch	
-Wellington Branch	
-Manawatu Branch	
-Canterbury Branch	
-Southland Branch	
-Nelson/Marlborough Branch	
Scotland	
The National Autistic Society in Scotland	
Scottish Society for Autism	
Wales	
The National Autistic Society in Wales	

Appendix D

Parental Perceptions of the Development of Autism in their Children

Web-based Questionnaire

Each child with autism is unique, and we are interested in learning about <u>your</u> child. Please complete the following questions on your child with autism. If you have more than one child diagnosed with autism, please complete a new questionnaire for each child.

Questions are presented in both closed-ended and open-ended formats. Closed-ended questions may be quickly answered by selecting responses from the provided list of choices. You may write up to 10 lines of text in response to the open-ended questions. Depending on how much information you share in the open-ended questions, it may take you between 30 and 60 minutes to complete the questionnaire.

1. Child's Gender:

- ☐ Male
- ☐ Female

2. Child's Age:

Years: ☐ Months: ☐

3. Child's Race

- ☐ White
- ☐ Black, African American
- ☐ Hispanic, Latino
- ☐ Asian
- ☐ Native American

- ☐ Bi-racial, mixed
- ☐ Other: _____

4. Where does your child live?

- ☐ Home, with parent(s)
- ☐ Home setting with grandparent or other relative
- ☐ Group home
- ☐ Faith-based home
- ☐ Hospital or nursing home
- ☐ Special school or treatment center
- ☐ Independent, in own home or apartment
- ☐ Other: _____

5. Where does your child spend his or her day? Please mark all that apply.

- ☐ Home
- ☐ Child-care center or babysitter
- ☐ Preschool or nursery school
- ☐ Elementary, middle, or high school
- ☐ Day-treatment center
- ☐ Sheltered workshop
- ☐ Vocational training or college
- ☐ Job/Supportive employment
- ☐ Other: _____

5a. Please indicate what kind of school your child attends

- ☐ Inclusive Classroom
- ☐ Special Education classroom at a public or private school
- ☐ School exclusively for children with special needs
- ☐ Vocational training or technical school

6. Within the autism spectrum, what is your child's primary diagnosis?

- ☐ Autism
- ☐ Asperger Syndrome
- ☐ Childhood Disintegrative Disorder
- ☐ Landau-Kleffner Syndrome
- ☐ Pervasive Developmental Disorder
- ☐ Rett's Disorder
- ☐ No clear diagnosis yet

7. What other diagnoses has your child received? (You may select more than one.)

- ☐ ADD/ADHD
- ☐ Brain Damage
- ☐ Fragile X
- ☐ Mental Retardation
- ☐ Seizure Disorder
- ☐ Sensory Integration Processing Disorder
- ☐ Tuberous Sclerosis
- ☐ Other: _____

8. Please mark the following characteristics that you first noticed as being different or delayed in your child and the approximate ages at which you noticed these differences.

☐ Lack of eye contact	Years:	Months:
☐ Lack of social smiling	Years:	Months:
☐ Failure to attach to caregiver	Years:	Months:
☐ Slowness in meeting motor milestones (e.g., sitting up, crawling, walking)	Years:	Months:
☐ Lack of responsiveness (e.g., to name, suggestions)	Years:	Months:
☐ Failure to use or respond to gestures (e.g., pointing, waving good-bye)	Years:	Months:
☐ Language delay	Years:	Months:
☐ Unusual physical behaviors (e.g., hand-flapping, rocking)	Years:	Months:
☐ Unusual interaction with or attachment to objects	Years:	Months:
☐ Lack of imaginative or pretend play	Years:	Months:
☐ Not playing with other children	Years:	Months:
☐ Other:	Years:	Months:

9. How old was your child when he or she received a formal diagnosis in the autism spectrum?

Years: Months:

10. Who gave the formal diagnosis of autism?

- ☐ Family physician/primary care provider
- ☐ Specialist doctor
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Other: _____

11. How many individuals or professionals did you and your child see in the process of getting an autism-spectrum diagnosis?

_____

12. How satisfied were you with the process of getting an autism-spectrum diagnosis?

- ☐ Extremely Satisfied
- ☐ Moderately Satisfied
- ☐ Not Satisfied

13. Has any other biological relative of your child been diagnosed with autism or a related mental health disorder?

Yes ☐ No ☐

Relative	Disorder
Mother	
Father	
Brother	
Sister	
Aunt/Uncle	
Grandparent	
Other Relative	

14. Where do you get your information about autism and your personal support? Please mark all that apply.

A. Personal Resources	**Get information here?**		**Get support here?**	
☐ Other parents of children with autism	Yes ☐	No ☐	Yes ☐	No ☐
☐ Family members	Yes ☐	No ☐	Yes ☐	No ☐
☐ Spouse or partner	Yes ☐	No ☐	Yes ☐	No ☐
☐ Friends, neighbors	Yes ☐	No ☐	Yes ☐	No ☐
☐ Religious community	Yes ☐	No ☐	Yes ☐	No ☐
☐ Other: _____	Yes ☐	No ☐	Yes ☐	No ☐

B. Professional Resources:	**Get information here?**		**Get support here?**	
☐ Physicians	Yes ☐	No ☐	Yes ☐	No ☐
☐ Educators	Yes ☐	No ☐	Yes ☐	No ☐
☐ Other Professionals (psychologists, case workers, etc.)	Yes ☐	No ☐	Yes ☐	No ☐
☐ Other: _____	Yes ☐	No ☐	Yes ☐	No ☐

C. Informational Resources:	**Get information here?**		**Get support here?**	
☐ Books	Yes ☐	No ☐	Yes ☐	No ☐
☐ Scientific Journals	Yes ☐	No ☐	Yes ☐	No ☐
☐ Webpages/E-mail list services	Yes ☐	No ☐	Yes ☐	No ☐
☐ Newsletters from	Yes ☐	No ☐	Yes ☐	No ☐

organizations focusing on autism

☐ Conferences	Yes ☐	No ☐	Yes ☐	No ☐
☐ Workshops	Yes ☐	No ☐	Yes ☐	No ☐
☐ Group or organizational meetings	Yes ☐	No ☐	Yes ☐	No ☐
☐ Other:	Yes ☐	No ☐	Yes ☐	No ☐

The following questions concern intervention methods for your child. There are many therapies for families to choose from, and new ones come available every day. But what works, and for which individual children? We want to know your experience with these therapies. Below is a list of interventions. For each one, simply click on the button to answer "Tried it?" "Using it now?" and "Effectiveness." (If you do not have enough room to indicate all the therapies you have tried, please feel free to list and discuss them in the final open-ended question.

15. Please complete the following information for each type of therapy listed. Regarding effectiveness, please use the following key:

4 = Child became worse

3 = No noticeable effect

2 = Child improved somewhat

1 = Child improved dramatically

Therapy	**Tried it?**	**Using it now?**	**Effectiveness**
(a) ABA, Behavior Modification, (Lovaas)	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(b) Auditory Integration Therapy	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐

(c) Detox (chelation)	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(d) Early Intervention Services	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(e) Floor Time	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(f) Music Therapy	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(g) Neurofeedback	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(h) Occupational Therapy	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(i) Options Program	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(j)Picture Exchange System	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(k) Physical Therapy	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(l) Positve Behavioral Support	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(m) Sensory Integration	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(n) Social Skills Training	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(o) Social Stories	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(p) Speech Therapy	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(q) TEACCH	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(r) Tomatis Program	Yes ☐ No ☐	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐

Therapy	Please Specify	Using it now?	Effectiveness
(s) Food Allergy Treatments	(1)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(2)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(t) Psychopharmacological Treatments (drugs)	(1)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(2)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(3)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(4)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(5)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(u) Special Diet	(1)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(2)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(v) Vitamin Supplements	(1)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
	(2)	Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(w) Other form of treatment		Yes ☐ No ☐	1☐ 2☐ 3☐ 4☐
(x) Other form of treatment		Yes ☐ No ☐	1☐ 2☐

			3☐ 4☐

Please complete the following about you, the caregiver.

16. Today's Date (use mo/day/year format)

17. Your Gender:

- ☐ Male
- ☐ Female

18. Your age in years:

19. Your race

- ☐ White
- ☐ Black/African American
- ☐ Hispanic/Latino
- ☐ Asian
- ☐ Native American
- ☐ Bi-racial/Mixed
- ☐ Other

20. Your Marital Status:

- ☐ Single
- ☐ Married
- ☐ Separated

- ☐ Divorced
- ☐ Widowed

21. Your Locale:

Select One

22. Years of education completed (12 years = high school graduate, 14 years = some college, etc.)

23. Approximate family income per year:

- ☐ less than $10,000
- ☐ between $10,000 and $25,000
- ☐ between $25,000 and $40,000
- ☐ between $40,000 and $55,000
- ☐ between $55,000 and $70,000
- ☐ between $70,000 and $100,000
- ☐ more than $100,00

24. Your relation to the child:

- ☐ Mother
- ☐ Father
- ☐ Step-mother
- ☐ Step-father
- ☐ Grandmother
- ☐ Grandfather
- ☐ Sibling

- [ ] Other Relative
- [ ] Foster parent
- [ ] Group-home caregiver
- [ ] Professional working with child:
- [ ] Other:

You have completed part one of this survey. Please click the button below to proceed to the open-ended questions.

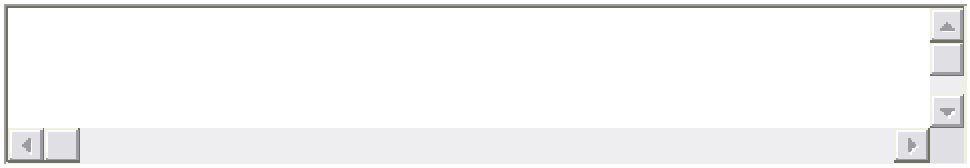
Before you submit the results to the first part of the survey, you may click here to review the informed consent page.

Proceed to part Two | Reset Form

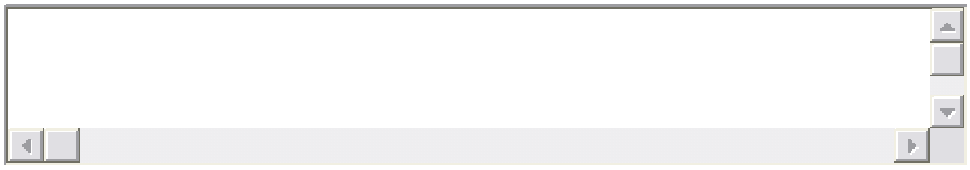
Open Ended Questions

Please limit yourself to about ten lines of text.

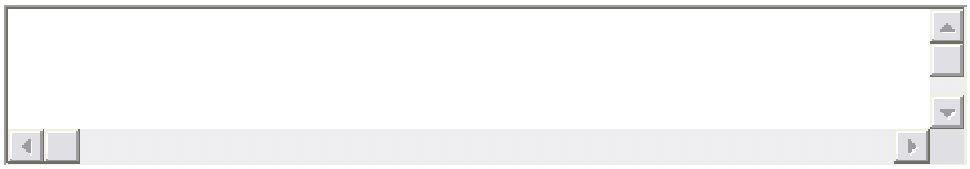
25. Do you feel that your child has always had characteristics of autism, or did they develop after a certain point or age? Please describe.



26. Do you ever notice your child making developmental improvements and then regressing, apparently "forgetting" new skills? If so, please describe.

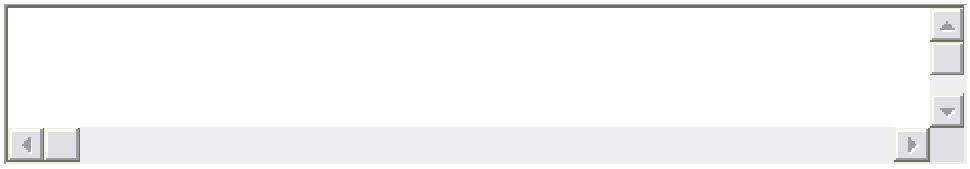


27. What is your personal theory of what causes autism, at least in your own child?

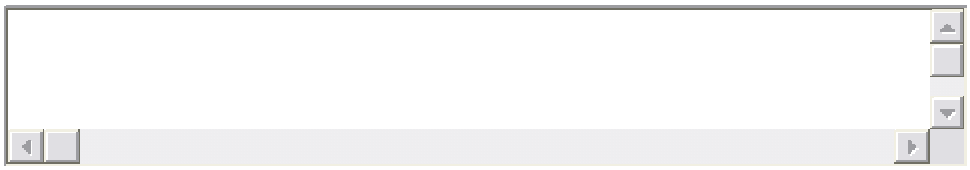


28. Describe your child's abilities today. What are his or her strengths, skills, difficulties?

29. What is your child like as a person?



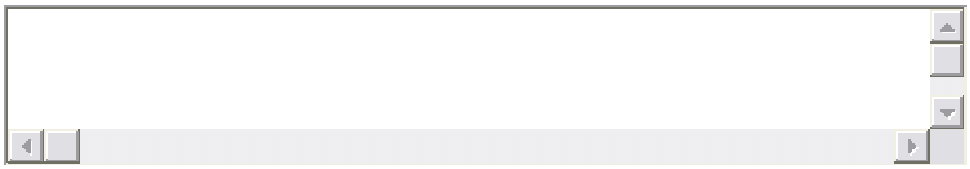
30. How has your child affected your life and your family's life?



31. What do you feel the future holds for you and your child?

32. What is it you like/dislike about the treatment(s) you're currently using?

33. Is there anything else you would like to share with us about your child?



34. Approximately how long did it take you to complete this survey?

Thank you for taking the time to complete our survey! Please click the button below to submit your results.

Submit Reset

Appendix E

VCU

Welcome to our Questionnaire on

Parents' Perceptions of the Development of Autism in their Children

Are you the parent or caregiver of a child with autism? Your child may be of any age, from infancy through adulthood. If so, please consider participating in our study on caregivers' perceptions of the development of autism in their children.

We are very interested in parents' views on the development of autism in their children. This information will help us to (a) learn more about potential early characteristics of the disorder, prior to a formal diagnosis, and (b) assess parents' ways of managing the progression of autism. We hope that you will assist us by participating in this research.

Below is a list of information that we would like for you to read before completing the questionnaire. If you have questions about any of these items, please feel free to contact me, Robin Goin (doctoral student in the Department of Psychology at Virginia Commonwealth University), through e-mail at s2rpgoin@mail1.vcu.edu or Dr. Barbara

Myers (associate professor in the Department of Psychology at Virginia Commonwealth University) at bmyers@vcu.edu or by phone at (804) 828-6752.

- By completing and submitting this questionnaire, you are agreeing to participate in a research study. All responses to questionnaire items will be completed using the Internet.

- It may take you anywhere between 30 and 60 minutes to complete the questionnaire, depending upon how much information you choose to share in the open-ended questions.

- All responses that you give will be completely anonymous. We do not ask for any contact or otherwise identifiable information, and we will not have any way to link your answers back to you. All information will be stored using identification numbers. We will not have your name or e-mail address and have no means of obtaining them. The only individuals who will have access to the data are Dr. Myers, myself, and the database managers.

- Results from this study will be presented collectively and may be published in journals, presented at professional conferences, and used for educational purposes. Participants will not be compensated as a result of any presentation or publication of the results.

- A possible risk is that you may feel uncomfortable about revealing information about your child and family.

- A potential benefit of participation is that you will have the opportunity to share your and your child's experiences with autism. You may also learn how other families view and manage their experiences with autism by reading the collective results of this study on an Autism Society of America (ASA) Virginia-chapter or The Autism Program of Virginia (TAP) website, e-mail list posting, and/or in a newsletter.

- Your choice to participate is strictly voluntary. You may choose (a) not to answer a certain question or questions and (b) not to submit your answers once you have completed the questionnaire.

- Please feel free to print out a copy of these informed consent items to keep for your records. Simply click the "print" icon in the toolbox menu of your browser.

- If you have any questions about this study, please feel free to contact Robin Goin at s2rpgoin@mail1.vcu.edu or Dr. Barbara Myers by e-mail at bmyers@vcu.edu, by phone at (804) 828-6752, or by mail at Department of Psychology, 808 W. Franklin St., Virginia Commonwealth University, Richmond, VA 23284-2018. If you have any specific concerns about your participant rights, you may also contact the Office of Research Subject Protection, 1101 E. Marshall Street, Room 1-023, Richmond, VA, 23298, by phone at (804) 828-0868, or by e-mail at orsp@vcu.edu.

Thank you for your time and participation. Your cooperation is greatly appreciated!

Please Click Here to Begin!

Appendix F

QUALITATIVE-DATA ANALYSIS
GUIDE FOR VALIDITY CHECKERS

Thank you for agreeing to serve as a validity checker for the qualitative-data analysis of this project! The purpose of your assisting in this process is to help assure the correct classification (coding) of participants' responses to select open-ended questions. Once coded correctly, these responses will be matched up with participants' additional data for further quantitative analyses.

You are asked to examine the responses to the first 3 questions in the database, which is provided on the enclosed computer diskette. These questions are:

#25: "Do you feel that your child has always had characteristics of autism, or did they develop after a certain point or age?"

Response codes for this question are:
Always = Believes that autism characteristics were present from birth
Not always = Believes that autism characteristics only or largely developed following a certain age and/or event
Not sure = Does not know when autism characteristics first appeared
Unclear = Unable to determine code based on response

#26: "Do you ever notice your child making developmental improvements and then regressing, apparently "forgetting" new skills?

Response codes for this question are:
Yes = Yes, the child does regress (may be one time with the initial onset, only with language or academics, or overall)
No = No, has not exhibited regression
Unclear = Unable to determine code based on response

#27: "What is your personal theory of what causes autism, at least in your own child?"

Response codes for this question are varied and broken down into 10 main categories:

Genetics = Implication of genes, heredity, or family history of autism/mental health disorders
External = Implication of vaccines, medications, environmental toxins, or other external/environmental triggers
Genetics + External = Implication of a combination of genetics (see above) and external factors (see above)
Biological = Implication of physiological or neurological factors, including immune deficiencies, metabolic issues, physical illnesses, and brain development

Genetics + Biological = Implication of a combination of genetics (see above) and biological factors (see above)
External + Biological = Implication of a combination of external factors (see above) and biological factors
Other = Implication of factors that include social influences, maternal illness/stress/medications, or child's birth difficulties/newborn medical traumas
Multiple = Implication of a combination of factors, either several factors or some combination of "Other" factors and those listed above
Don't know = Participant does not have a personal theory of causation
Unclear/Unsure = Participant vacillates between causes (typically using "this OR that" statements), or unable to determine code based on response

You will only need to examine those responses from a randomly selected 20% of the entire sample. The ID numbers selected for your examination are listed below.

22	79	130	153	207	264	314	357
24	84	132	161	213	274	317	365
36	85	135	164	219	287	319	369
39	94	139	176	221	288	327	370
47	105	141	178	227	290	331	380
54	116	145	184	229	292	332	381
56	124	147	185	240	300	335	388
68	125	148	187	253	301	337	396
70	127	150	189	256	305	341	400
73	128	152	201	260	313	343	405

You are also provided with a hard-copy table that lists the codes that have been given for participants' responses. Read the participant's responses to the first 3 questions in the database, then look on the hard-copy table to read the code that has been given as an interpretation of that participant's answer. Decide if you feel that the assigned code is an accurate representation of this answer. Sometimes it may be helpful to examine the participant's responses to the other two questions if you are struggling with how to think about one response. If you feel that the given code is accurate, do nothing and move onto the next selected ID number and repeat this process. **If you DO NOT feel that the code is an accurate representation of a given answer, please put a star by that code on the hard-copy table**. When you return the table and diskette to me, we will set aside time to discuss any discrepancies. Together, we will decide an appropriate code for any responses in which there are differences in our interpretations.

Again, thank you for your cooperation with this process! If you have any questions or concerns, please let me know by calling me at either 213-0727 or 628-2268 or e-mailing me at s2rpgoin@mail1.vcu.edu .

Vita

Robin P. Goin was born on November 15, 1972, in Austin, Texas. She was graduated from Arlington Heights High School in Fort Worth, Texas, in 1991, and received her Bachelor of Arts in Psychology from Texas Woman's University in Denton, Texas, in 1995. She continued her education in Child and Family Studies at The University of Tennessee, Knoxville, and was graduated with her Master of Science degree in 2000. She has attended Virginia Commonwealth University since the fall of 2000 and plans to participate in postdoctoral studies at the Virginia Institute for Psychiatric and Behavioral Genetics following graduation.