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Early Detection and Intervention for Infants at risk of Autism Spectrum Disorders

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Abstract

Autism is a developmental disorder that is characterized by abnormal social interactions and communications as well as repetitive and restricted activities and interests. There is evidence of a genetic component, as 5% of younger siblings are diagnosed if their older sibling has been diagnosed. Autism is generally not diagnosed until age 3 at the earliest, yet it has been shown that early intervention for children with autism can greatly increase their functioning. Because of this, it is important that symptoms of autism are identified as early as possible so that diagnosis can occur as soon as possible to allow these children the earliest intervention.

This thesis was divided into two parts. The first looked at the psychometrics of two proposed measures, the Parent Observation Checklist (POC), administered monthly, and the Infant Behavior Summary Evaluation (IBSE), administered bimonthly, to see if they can be used with the infant population to identify autistic symptoms in infants who are at high risk for autism or related problems because they have an older sibling with autism. Study 1 reported acceptable psychometric properties of both the POC and IBSE in terms of test-retest reliability, internal consistency, construct validity and predictive validity. These results provide preliminary evidence that parent report measures can help to detect early symptoms of ASD in infants. The POC was shown to differentiate infants who were diagnosed from a matched group that was not diagnosed by 3 years of age.

The second part of this thesis involved a telephone interview of parents who reported developmental and/or behavior problems in their high-risk infants that may be early signs of Autism Spectrum Disorder (ASD). During the interview, a service questionnaire was administered to see what interventions (including strategies recommended by the researchers) their at risk infants and affected older siblings were receiving, how satisfied the parents were with them and how effective they felt the interventions were.

Study 2 also yielded promising results. Parents utilized a variety of services for at risk infants and children with ASD. The interventions included empirically validated early intervention (e.g., ABA) to non-empirically validated treatments (e.g., diet therapy). The large number of non-empirically validated treatments parents used was surprising, yet parents reported being involved and satisfied, and thought that the services were effective. Parents' perceptions of their stress levels went down slightly and feelings of competence rose when they accessed services for their infants.

Overall, the results of this thesis provide new evidence that parent-report methods hold promise as early detection instruments for ASD in at-risk infants. More research is needed to further validate these instruments as well as to understand the variables related to the parents' choice of early intervention for their at risk and affected children.

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General Introduction

What is Autism?

Autism is a developmental disorder seen as far back as 1747 when a middle-aged man was observed as having deficits in social relationships, along with severe mental retardation and abnormal language (described as what is now known as echolalia) (Wolff, 2004). First described in 1943 by Kanner (Filipek et al., 1999), autism is marked by the presence of abnormal or impaired social interactions (e.g., poor eye contact and nonverbal communication), as well as poor awareness of others' emotions and communications (e.g., poorly developed language, echolalia), along with restricted and repetitive activities and interests (Fein, Robins, Liss, and Waterhouse, 2001). These characteristics define the diagnostic criteria for autistic disorder (AD) in DSM-IV-TR (American Psychiatric Association [APA], 2000). In order for a diagnosis to occur, symptoms must be apparent through delays or abnormal functioning by the age of 3 in at least one of "social interactions, language as used in social communication, or symbolic or imaginative play" (APA, 2000, p. 71).

Autism disorder typically occurs three to four times more frequently in males than females (Filipek et al., 1999). As the severity of mental retardation increases, this ratio diminishes (APA, 2000; Croen, Grether, & Selvin, 2002; Filipek et al., 1999; Fombonne, 2003) as illustrated by Fombonne (2003) as 1.9:1. In the same study conducted by Fombonne (2003), it was illustrated that the prevalence of mental impairment was 70% (approximately 1700 out of 2400 participants). Thirty percent had mild to moderate impairment while 40% had severe to profound impairment.

Comorbid Conditions

There are a variety of comorbid conditions that accompany autism including, most often, an associated diagnosis of mental retardation (MR) (APA, 2000; Croen et al., 2002; Fein et al., 2001; Fombonne, 2003) in approximately 75% of those with autism (Croen et al., 2002). Epilepsy was another commonly cited comorbid condition, although prevalence rates were not listed (APA, 2000;

Fein et al., 2001; Fombonne, 2003). Other possible comorbid conditions include Tourette's syndrome and schizophrenia (Fein et al, 2001), specific biomedical conditions (APA, 2000; Fein et al., 2001), tuberous sclerosis and fragile X (Fombonne, 2003).

Genetic Risk

There is an increased risk (5-8%) for autistic disorder in siblings (APA, 2000; Wolff, 2004). Risks of developmental difficulties are also higher in siblings (APA, 2000). Twin studies strongly suggest a genetic basis for autism (Wolff, 2004). Filipek et al., (1999) reviewed some twin studies in which it was shown that Folstein and Rutter, in 1977, reported a concordance rate of 36% for infantile autism between 11 pairs of monozygotic (MZ) twins, with no concordance rate between 10 pairs of dizygotic (DZ) twins. It was shown, though, that 82% of the MZ twins, and 10% of the DZ twins were concordant for some form of cognitive, social, or language deficits. Filipek et al., (1999) also cited more recent studies where it was shown that 28 MZ twin pairs showed a "concordance rate of 60% for DSM-IV *autistic disorder*, 71% for the broader spectrum of PDD or atypical autism, and 92% for an even broader phenotype of social and communication deficits with stereotyped behaviors" (Filipek et al., 1999, p.457).

Possible Primary Deficits

It has been the focus of research in recent years to try and identify the primary deficit of autism. Fein et al. (2001) have reviewed a few studies and have shown from their results that cognitive deficits (e.g., language, memory and attention) are unlikely to be primary deficits. They have also shown that although executive function and theory of mind are hindered in autism, they are also unlikely to be the primary deficit. Fein et al. (2001) also looked at possible biological causes of autism through the review of prior research, and also cannot identify a primary deficit. They went on to hypothesize that autism is possibly a mix of a variety of deficits, and is a "heterogeneous disorder" (p.32). The DSM-IV-TR (APA, 2000) reports that laboratory findings show abnormal EEG readings.

There have been a variety of genetic studies that have attempted to isolate certain genes (Gillberg, 1998, Chudley et al., 1999; Wolff, Clifton, Karr, & Charles, 2002). Researchers have been identifying possible candidate genes (identified on the basis of their potential role in the pathophysiology of ASD) with some success (Menold, 2001; Nurmi et al., 2001). The results that have been produced thus far are promising, yet there has been no determined genetic or biological mechanism.

Autism Spectrum Disorders

Autism is a spectrum disorder with a variety of disorders on it. Filipek et al. (1999) defined autistic spectrum disorders (ASD) as referring to “a wide continuum of associated cognitive and neuro-behavioral disorders, including, but not limited to, three defining features: impairments in socialization, impairments in verbal and nonverbal communication, and restricted and repetitive patterns of behavior” (p. 439). This implies that although autism is included in ASD, there is also a wide range of other disorders that fall on the spectrum that are not autism, according to the DSM-IV-TR. Other disorders on the ASD spectrum include pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger’s disorder, Rett’s disorder, and Childhood disintegrative disorder.

According to the DSM-IV-TR (2000), a diagnosis of PDD-NOS is made when “severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interest, and activities, but the criteria are not met for a specific PDD, schizophrenia, schizotypal personality disorder, or avoidant personality disorder” (p.84).

A diagnosis of Asperger’s syndrome (AS) should be made when there is severe and sustained impairment in social interaction, there are restricted and repetitive patterns of behavior, interests, and activities, and these have a “clinically significant impairment in social, occupational, or other important areas of functioning” (APA, 2000, p.80). In contrast to a child with autism, a child

with Asperger's syndrome will have normal language development and cognitive functioning at age-appropriate times, as well as "adaptive behavior and curiosity about the environment in childhood" (p.81). The disorder should also not be better defined as PDD-NOS or schizophrenia.

Rett's disorder is also on the autism spectrum, but has been diagnosed only in females (APA, 2000). DSM-IV-TR (2000) recommends that a diagnosis of Rett's disorder should be made when there has been a deceleration of head growth between 5 and 48 months, when previously acquired purposeful hand skills have been lost between the ages of 5 and 30 months (with the development of stereotyped hand movements), when there has been a loss of social engagement early in the course of the disorder, when poor gait or trunk movement emerges, and when severely impaired language development and psychomotor retardation emerge. Rett's differs from AD in its above-mentioned sex ratio, as well as in deceleration of head growth, the loss of purposeful hand movements, and the appearance of poor gait (APA, 2000). The disorder should also not be better addressed as CDD, AS or AD.

Childhood disintegrative disorder (CDD) is another on the ASD spectrum. CDD has a marked regression in many areas of functioning following a period of at least two years normal development, i.e. age-appropriate communication, social relationships, play and adaptive behavior (APA, 2000). After 2, but before 10, "the child has a clinically significant loss in at least 2 of the following areas: expressive or receptive language, social skills or adaptive behavior, bowel or bladder control, play, or motor skills" (APA, 2000, p.77). In order for diagnosis to occur, it is also not better accounted for by another specific PDD or by schizophrenia. It is also known as Heller's syndrome, dementia infantilis, or disintegrative psychosis (APA, 2000).

It has been reported that autism spectrum disorders are "are not rare disorders, but instead are more prevalent in the pediatric population than cancer, diabetes, spina bifida, and Down syndrome" (Filipek et al., 1999, p. 440). Prevalence rates vary from 10-20 per 10,000 to 30.8/10,000

for autistic disorder alone (Filipek et al., 1999); DSM-IV-TR (APA, 2000) reported a prevalence rate of autism at 5/10,000 individuals. In 2005, Fombonne updated prevalence rates to 13/10,000 for autistic disorder, and 60/10,000 for all PDD's. He referred to the estimate of PDD's as the "best estimate for the prevalence of PDD's currently available" (Fombonne, 2005, p.287).

Purpose of Current Studies

This research was conducted for two primary reasons. The first was to identify psychometric properties of low-cost, parent report measures for detecting autism during infancy. The second was to begin to catalogue and evaluate interventions that parents utilize when early symptoms of autism are detected in their infant. Our intervention, which consisted of advice and support from the interviewer, was evaluated alongside any others that the parents chose to utilize. The children that participated in the study were tracked specifically because they were at risk for autism due to having an older sibling with autism. As part of the ongoing Autism Spectrum Disorders-Canadian American Research Consortium (ASD-CARC) prospective study, the infants were tracked through parental report and home video, and not through clinical measures, as was previously done in a study by Zwaigenbaum et al. (2005). The additional procedure in this thesis was a phone call to participating parents (who reported that their infants were showing developmental and/or behavioral problems) to complete the service questionnaire. This research was an ecologically valid, naturalistic assessment of interventions these infants received, as chosen by the parents. We monitored what interventions the families chose to select on their own (e.g., diet, sensory integration) in addition to behavioral and developmental recommendations provided by the research team.

Study 1: Initial validation of parent-report measures of early symptoms of ASD in at-risk infants

Common Concerns in the First Years

Although autism usually is not diagnosed until after 24 months of age, many parents suspect something is wrong before that (Gray & Tonge, 2001). The most common concerns raised in the first two years of life, prior to diagnosis, are language delays, speech problems, and social development. Symptoms are usually always present before 3 years of age (APA, 2000; Filipek et al., 1999). Woods and Wetherby (2003) identified variability of behavior, lack of appropriate referrals when concern is expressed and/or the family's lack of knowledge or access of the services available to them as primary factors in precluding early detection of autism. Autistic disorders follow a continuous course throughout life, though communicative language and high IQ are important prognostic features by the age of 5 (APA, 2000; Fein et al., 2001), i.e., if children possess these characteristics, they generally have better outcomes. School-age children may show developmental gains, while some adolescents may show some behavioral improvements while others may see deteriorations (APA, 2000).

Diagnosis and Early Identification

It has been previously demonstrated that early intensive behavioral intervention (EIBI), when initiated prior to the age of 5 can lead to great improvement in autistic symptomology (Lovaas, 1987), thus it is beneficial to identify symptoms and receive a diagnosis as early as possible. But can the diagnosis be made early (i.e., under the age of 2) and continue to be stable at older ages? Cox et al. (1999) showed that of the nine children they diagnosed as having autism at 20 months using the Checklist for Autism in Toddlers (CHAT, Baron-Cohen et al., 2000) as a screening tool as well as the Autism Diagnostic Interview-Revised (ADI-R, Lord et al., 1994) (a "gold-standard" diagnostic instrument, Filipek et al., 1999), and a variety of other standardized measures, none had a diagnosis outside the ASD spectrum at 42 months. Notably, there were only 2 false negative diagnoses made

where those children were given a diagnosis of other PDD at 20 months, and at 42 months, received a diagnosis of autism. Cox et al. (1999) noted though, that by taking a spectrum approach, there were no false negatives.

Robins, Fein, Barton and Green (2001) validated the Modified Checklist for Autism in Toddlers (M-CHAT) and supported its use as a screening measure for autism. The measure, as well as its subsets of the 6 most discriminating measures, was reliable and was able to differentiate those with autism/PDD and all other children, as those with autism/PDD failed more items than all of the other children. They were also significantly different on all of the items, except for enjoying being swung/bounced. Further research conducted on the M-CHAT by Eaves, Wingert, and Ho (2006), did not get quite the same results. They found a similar high sensitivity as Robins et al. (2001) did, but a lower specificity when the two were compared. Eaves et al. (2006) also did not find a significant score difference between ASD and non-ASD children, as reported by Robins et al. (2001). Although there was a significant positive correlation reported between the M-CHAT and the CARS, there was no relation that was determined between the M-CHAT and the DSM-IV score (Eaves et al., 2006).

Eaves and Ho (2004) diagnosed autism at 2.5 years of age in 49 children suspected of having autism. The ADI-R has a high sensitivity and specificity to identify autism in children with a mental age of greater than 18 months, and the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 2002) can show significant differences between children with autism and those of normal development at 2 years of age. Eaves and Ho (2004) monitored the children and then re-evaluated them 1.5 years later where it was shown that 79% of the children stayed in the same diagnostic category, while approximately 10% changed in each direction of diagnostic severity. Eaves and Ho (2004) go on to note the importance of monitoring possible early symptoms as those children who have difficulties socially and with language at the age of 2 will rarely grow out of it without effective intervention.

The Screening Tool for Autism in Two-year-olds (STAT) is another screening measure that is being used. Stone and Henderson (2006) identified through administration of the measure to infants at risk for autism that by revising the scoring algorithm, the STAT could be used with children as young as 15 months to discriminate between those who would receive an ASD diagnosis and those who would not.

The Autism Observation Scale for Infants (AOSI) can distinguish siblings with ASD from undiagnosed siblings and controls as early as 12 months (Brian, Zwaigenbaum, Roberts, Szatmari, & Smith, 2006). This was determined by the collection of data from with infants at the age of 12 and 18 months (Brian, Zwaigenbaum, Roberts, Szatmari, & Smith, 2006).

Eaves et al. (2006) also reported on psychometric findings of the Social Communication Questionnaire (SCQ). They found that this measure had similar sensitivity reports as previous research, but that the specificity was lower. There was also a significant positive correlation between the SCQ and the CARS (Eaves et al., 2006), indicating that the SCQ could be a viable screening measure.

A new measure was also validated for use by Adrien, Roux, Couturier, Mavly, Guerin, Debuly, et al. (2001) called the Behavior Function Inventory (BFI). The construction of this measure was done so that there were precise and clear definitions of each characteristic behavior, attributing an equal number of items to each functional category, and making it easily applicable to clinical and research practice (Adrien et al., 2001). Adrien et al. (2001) validated the measure with 131 developmentally delayed children ranging in age from 23 to 147 months, with diagnoses of AD, MR, or PDDNOS. Psychologists experienced with PDD administered the measure. It was determined that the BFI gives a precise evaluation of autistic symptoms and that the items included were reliable (Adrien et al., 2001). Limitations included the fact that specialized staff are required to administer

the BFI, and the fact that it is a 2-day observation, thus it could not be a routine measure given at appointments.

A parent-report screening tool, the Developmental Behavior Checklist – Primary Carer Version (DBC – P), is a 96 item screening tool that is quick and easy (Gray & Tonge, 2005) to use. Parents complete the form, and, because it can differentiate those with autism and DD from those with DD and no autism, parents can get the appropriate referral (Gray & Tonge, 2005). The sensitivity, specificity and positive predictive values are all acceptable for developmental screening (Gray & Tonge, 2005).

As can be seen from above, there are many measures that are being developed, as well as a few that have been published attempting to detect early symptoms of autism in at risk infants. There have been many screening tools recently developed and they are able to differentiate those with AD and those who are either typically developing or developmentally delayed. This is a large step in the right direction for early identification of at risk infants.

Early Features of Autism: Retrospective Studies

Investigators have also attempted to identify early features of autism in the first two years of life (see Table 1). From the review of various articles, using retrospective home movies, retrospective parent reports, as well as controlled observations, Gray and Tonge (2001) identified a variety of early features common in children who later go on to be diagnosed as autistic. These include deficits in social interactions such as lack of facial expressions, gestures and eye contact. Deficits in communication were also noted such as lack of babbling, gaze monitoring, and imitation; also reported were unusual or repetitive preoccupations, mouthing of objects, acting deaf, sensitivity to noise, sleep problems, self-injury, lack of responsiveness to name and behavioral variability. Other studies found that infants later diagnosed as autistic oriented less to their name (Osterling & Dawson, 1994; Osterling, Dawson, & Munson, 2002; Werner, Dawson, Osterling, & Dinno 2000), had a lack

of gestures, including pointing (Osterling et al, 2002; Osterling & Dawson, 1994), lack of joint attention behaviors (Baranek, 1999; Osterling et al, 2002; Osterling & Dawson, 1994; Werner et al 2000; Woods & Wetherby, 2003), deficits in early social and prelinguistic behaviors (Osterling et al, 2002; Osterling, & Dawson, 1994; Woods & Wetherby, 2003), lack of showing objects (Woods & Wetherby, 2003), self-stimulation (Osterling & Dawson, 1994), excessive mouthing of objects and social touch aversions (Baranek, 1999), more frequent repetitive actions, as compared to typically developing children (Osterling et al, 2002) as well as a lack of response to voice, lack of understanding gesture, and unusual use of others' bodies (Baranek, 1999; Osterling & Dawson, 1994; Osterling, et al., 2002; Werner, et al., 2000).

Wetherby, Woods, Allen, Cleary, Dickinson et al. (2004) identified 9 markers through videotape coding that differentiated ASD from typical development (TD) and developmental delay (DD). Those were the lack of: appropriate gaze, warm and joyful expression, sharing enjoyment or interest, response to name, showing, coordination of gaze, gesture, sound and facial expression, unusual prosody, repetitive movements (body, arms, fingers), and repetitive movements with objects. The lack of response to contextual cues, lack of pointing, lack of vocalizations with consonants and lack of playing conventionally with many toys differentiated those with ASD from the TD group.

Crais, Watson, Baranek, Boyd, Miller, et al (2006) recently identified through home videotapes that it can be seen that between the ages of 9 and 12 months, those infants with ASD had deficits in behavior regulation and joint attention gestures, whereas Watt, Wetherby, Barber, McCoy, and Book (2006) found that repetitive movements with the body were seen between the ages of 18 and 24 months, differentiating between those diagnosed with ASD versus those diagnosed DD or those who TD. In a similar study, Shumway, Wetherby, Kahn, Plumb and McCoy (2006), also looked at videotapes to find that those with ASD has distinct patterns of communication between the

ages of 18 and 24 months (such as lower rate of total acts, acts with game and acts with vocalizations) than did those who were diagnosed with developmental delay or typical development.

Table 1

Early Signs and Features of Autism: Retrospective Studies

Study	Participants	Measures	Observation	Design	Early Features Identified
Osterling & Dawson, 1994	22 children 11 autistic (10 males, 1 female) 11 typically developing (10 males, 1 female) Age: 12 months old	CARS, BSID, M-P scales, LIPS, SBIS, WISC-R	Videotapes of 1 st birthday	Retrospective analysis	Orient less to name, lack of gestures, lack of joint attention, deficits in early social and prelinguistic behaviors, self-stimulation
Baranek, 1999	32 children 19 males 13 females Ages: 9-12 months	CARS, VABS	Videotapes	Retrospective video analysis	Lack of joint attention, excessive mouthing of objects, social touch aversion
Werner, Dawson,	30 infants 15 ASD (8	VABS-CD, M-P scales,	Videotapes	Retrospective analysis	Orient less to name, and lack

Osterling, & Dinno, 2000	autistic, 7 PDDNOS) 15 typically developing Ages: 8-10 months	LIPS, SBIS, WISC-R			of joint attention
Osterling, Dawson & Munson, 2002	54 children 20 with ASD (18 males, 2 females) where 14 had MR and 6 had normal intellectual ability 14 with MR (10 males and 4 females) 20 typically developing (18 males, 2	SBIS, CARS, VABS, structured, standardized interviews with parents	Videotapes of birthdays	Retrospective analysis	Orient less to name, lack of gestures, lack of joint attention, deficits in early social and prelinguistic behaviors, more frequent repetitive actions

females)

age range:

2.5 to 10

years of age

Wetherby,	54 children	VABS,	Videotapes	Retrospective	Lack of:
Woods,	(18 ASD, 18	ADOS,	of the	video	appropriate
Allen,	DD and 18	MSEL;	behavior	analysis	gaze; warm and
Cleary,	TD) from	CSBS DP	sample		joyful
Dickinson,	13-26	Infant and			expression;
et al. (2004)	months	Toddler			sharing
		Checklist			enjoyment or
					interest;
					response to
					name; showing;
					coordination of
					gaze, gesture,
					sound and
					facial
					expression;
					unusual
					prosody;
					repetitive
					movements
					(body, arms,

fingers);
 repetitive
 movements
 with objects;
 lack of
 response to
 contextual
 cues;lack of
 pointing; lack
 of vocalizations
 with
 consonants;
 lack of playing
 conventionally
 with many toys

Crais,	56 infants	Preschool	Videotapes	Retrospective	Those
Watson,	between 9	Vineland		video	diagnosed with
Baranek,	and 12	scores		analysis	ASD had a lack
Boyd,	months (27				of gestures
Miller, et al.	ASD, 3 DD				compared to
(2006)	and 7 TD);				the DD and TD
	29 infants				comparison
	between 15				groups
	and 18				

	months (19 ASD, 3 DD, 7 TD)				
Watt, Wetherby, Barber, McCoy, & Book (2006)	123 children between the ages of 18 and 24 months (50 ASD, 50 TD and 23 DD)	None	Videotapes	Retrospective video analysis	ASD group had significantly higher number of repetitive movements with object, as well as repetitive movements with the body; they also had a higher rate of total repetitive and stereotyped behaviors
Shumway, Wetherby, Kahn, Plumb, & McCoy (2006)	123 children between the ages of 18- 24 months (50 ASD, 50 TD, and 23	None	Videotapes	Retrospective video analysis	Those with ASD showed significantly less total acts, acts with gaze, and acts with

DD)

vocalizations

than those with

TD or DD; the

ASD group

also used less

deictic and

representational

gestures

Note: CARS: Childhood Autism Rating Scale, BSID: Bayley Scales of Infant Development, M-P scales: Merrill-Palmer Scales, LIPS: Leiter International Performance Scales, SBIS: Stanford Binet Intelligence Scale, WISC-R: Wechsler Intelligence Scale for Children - Revised, VABS: Vineland Adaptive Behavior Scales, VABS-CD: Vineland Adaptive Behavior Scales – Communication Domain; ADOS: Autism Diagnostic Observation Scale; MSEL: Mullen Scales of Early Learning; CSBS DP: Communication and Symbolic Behavior Scales Development Profile

Early Features of Autism: Prospective Studies

There is only one study that has looked at autism in infants (in the first year of life) and tried to identify early markers of the disorder prospectively (Zwaigenbaum et al., 2005). The researchers looked at infants at biological risk for autism because they had an older sibling who was already diagnosed, as well as a low risk group and a control group of similarly matched infants through the use of a longitudinal prospective study. They focused primarily on extensive clinical assessments through various measures such as the Autism Observation Scale for Infants (Brian et al., 2006) (which the authors developed due to a lack of measures detecting autistic symptoms in infants), as well as measures that assessed temperament, language and cognitive development. They found that infants who scored above the threshold on the Autism Diagnostic Observation Scale (ADOS – Lord

et al., 2000) at 24 months, had been quite passive, had fewer imitations, were less responsive to their name, as well as efforts to gain their attention between the ages of 6 and 12 months. Informal home and clinical observations showed they also had fewer vocalizations (Zwaigenbaum et al., 2005). At 12 months, those same infants who scored above the threshold on the ADOS at 24 months, were shown to have less eye contact, abnormal visual attention and social responsiveness, as well as excessive visual fixation. They also had unusual use of play materials, were irritable, and displayed intense sensory responses in addition to delays in verbal and pre-verbal skills (Zwaigenbaum et al., 2005).

There also have been a few other prospective studies in which children in their second year of life were followed until they were diagnosed. These prospective studies revealed a number of features consistent with the retrospective studies. At 18 months, the failure of three key items on the CHAT, a common screening tool for autism, was linked to a future diagnosis of autism (Baron-Cohen et al, 1996; Baron-Cohen, Allen, & Gillberg, 1992; Woods & Wetherby, 2003). These key items were protodeclarative pointing, gaze monitoring, and pretend play (Baron-Cohen et al., 1996; Baron-Cohen, Allen, & Gillberg, 1992; Woods & Wetherby, 2003). In fact, failing two or more of lack of pretend play, protodeclarative pointing, social interest, joint attention and social play on the CHAT at 18 months has been shown to be indicative of an autism diagnosis at the age of 30 months (Baron-Cohen, Allen, & Gillberg, 1992).

According to Osterling and Dawson (1994) “how often a child looked at others was the single best predictor of a child’s later diagnosis” (p.256), while Robins et al. (2001) described looking at behaviors that reflect empathy, pretend play, joint attention and imitation, when practitioners were considering an autism diagnosis in young children.

There have recently been more prospective studies run trying to identify autism symptoms earlier. For example, Ozonoff (2006) indicated that her research is suggesting that social orientating

as well as face and affect processing can be detected in infant siblings of children with autism as early as 12 months. Ozonoff (2006) also indicates that these same siblings present unusual phenotypes (i.e., early language, joint attention, social engagement as well as imitation).

Brian et al. (2006) also identified some markers prospectively that differentiate those siblings who would be diagnosed with ASD versus those who would not be. They did this through the administration of the AOSI and found the following markers: atypical visual tracking, orienting to name, imitation, eye contact, social smile, behavioral reactivity, and social interest and affect as differentiation between siblings with ASD, versus those without ASD and low risk controls.

A population based sampling procedure was also used prospectively (Wetherby, 2006), by screening a general pediatric sample for communication delays. Parent-report as well as a screening and referral processes were part of the study to determine risk, in which case autism-specific parent report measures were used. There were no preliminary results presented, but this screening could be promising to catch more at risk children.

Lack of Research in Early Detection and Justification for Current Research

To date, Zwaigenbaum et al. (2005) is one of the few studies that have tracked autistic symptoms in at-risk infants in their first year of life. As has been demonstrated, early intervention for children with autism is important for their future outcomes, yet the problem remains that autism is usually diagnosed much later, and thus young children may not benefit to the full degree that they could from early interventions. Further research is greatly needed to identify the early signs of autism in high-risk infants, and intervene as early as possible, preferably before diagnosis to prevent autistic behaviors and developmental delay. Research is just starting on designing a less expensive, more readily available screening tool, based on parental report. Parent report measures have been shown to be a cost-effective way to screen for developmental problems in young infants (Glascoe, Foster, & Wolraich, 1997). Once such instruments are available, then it is likely that more studies will evaluate

the effects of very early intervention on pre-diagnostic infants who are beginning to show behavioral and developmental problems characteristic of autism.

The current study is important to run, because, as previously mentioned, there are very few published measures that have attempted to detect autism symptoms in infants under 12 months of age (Zwaigenbaum et al, 2005). The Zwaigenbaum study relied on extensive expert assessment of the infant in a specialized clinic, and studies are just beginning to validate less costly parent-report measures. In this study, we determined the reliability and validity of parent-report measures that are being used in the ASD-CARC prospective study, under the direction of M. Feldman and J. Holden (co-principal investigators). If the measures are valid, then autistic symptoms may be able to be identified by parents earlier in any child, leading to earlier and potentially more effective intervention, giving children the best chance at reversing the developmental course of ASD.

Research Questions and Hypotheses

The research question was: is parent report a feasible, reliable, and valid method of tracking possible early signs of ASD in biologically at-risk infants? This question was addressed through the following hypotheses:

Test-retest reliability. It was hypothesized that an acceptable correlation of .8-.9 will be seen for 1-month test-retest reliability for both the Parent Observation Checklist (POC) and the Infant Behavior Summary Evaluation (IBSE).

Internal consistency. A correlation of .7-.9 will be seen to establish internal consistency, using Cronbach's *alpha* and split-half reliability.

Construct validity. The POC and IBSE will show *convergent* validity as demonstrated by correlations in the .8-.9 range with each other, that they will each show moderate correlations, (in the .4-.6 range) with the Ages and Stages Questionnaire (ASQ) communication and social subscales, and that they will each show *divergent* validity with low to no correlations with the ASQ motor subscale.

The ASQ is a questionnaire developed by Bricker and Squires (1999) which monitors infant development through a variety of questionnaires based on infant age sequences.

Predictive validity. It was also hypothesized that the POC will be able to show predictive validity of an ASD diagnosis through the monitoring of children over 3 years to see if diagnosed children had significantly higher POC scores (within the first 12 and 24 months of life) than a matched group of undiagnosed at-risk infants.

Method

We began a preliminary analysis of the psychometric properties of the POC and IBSE with approximately 80 high risk infants, between 1 to 73 months of age as of November 2005, as neither measure has yet been tested with an infant population. The ASQ was not subjected to these tests as it has already been shown to display sound psychometric properties through prior research (Bricker & Squires, 1999). The data was provided to us through the prospective study, and the authors did not administer the measures described below. As described above, we addressed test-retest and interrater reliability, internal consistency, construct and predictive validity.

Participants

The participating families in this research were those who have already been part of the ASD-CARC prospective study. These 80 participating families have at least 2 children, 1 with ASD and a younger infant who is at risk for ASD. The age range of the children who were already diagnosed was 3 years, 3 months of age to 15 years, 11 months. The age range of the infants was 1 month to 3 years, 3 months. The mean age when the infants first took the POC was 5.1 months, while their last POC was at an average of 17.2 months. The mean age when the infants received their first IBSE was 9.04 months while the mean age of their last IBSE was 23.36 months. We did not have access to any other demographic information of the participants thus it is not known how representative this sample is of all families with one autistic child and another at risk.

Materials

Parent Observation Checklist (POC). The primary caregiver of the infant (usually the biological mother) filled out this questionnaire (see Appendix A) monthly, online or by phone interview.

The POC (Feldman and Ward, 2001) consists of 61 questions, rated on a 4-point scale, where 1 is typical development (i.e., no problems), and 4 would indicate severe autistic symptoms (1/2 scores are allowed). The POC was created by extending “downward” the age range of the items in the subscales of the Childhood Autism Rating Scale - CARS (Schopler et al., 2002). The initial items were distributed to autism researchers who were asked to indicate whether they thought the item was reflective of the area of development identified by the name of the subscale and at what age an infant may demonstrate the developmental skill or a problem with it (e.g., responding to name; vocal imitation). The researchers also were given the opportunity to suggest new items.

Like the CARS, the POC is able to portray the degree of possible autistic symptoms the infant is exhibiting, even if the child does not score above the cut-off on existing instruments. The POC subscales (borrowed from the CARS) are: I. Relating to People, II. Imitation, III. Emotional Response, IV. Body Use, V. Object Use, VI. Adaptation to Change, VII. Visual Response, VIII. Listening Response, IX. Taste, Smell, and Touch Response and Use, X. Fear and Nervousness, XI. Verbal Communication, XII. Nonverbal Communication, XIII. Activity Level, XIV. Level and Consistency of Intellectual Response, and XV. General Impressions. Note that subscale validity was not tested in this study.

Infant Behavior Summary Evaluation (IBSE). Adrien et al. (1992) developed the IBSE through retrospective videotapes of children (aged 6 through 48 months) who were or later became autistic. There are 19 validated items, which are scored on a scale of 0 to 4 where 0 is typical development and 4 is indicative of ASD (see Appendix B). According to Adrien et al. (1993), there were 14 items

that differentiated between infants who developed autism, and matched infants who did not develop autism. Although the IBSE was originally designed as an observation instrument and used to detect autism in children 18 months or older, we adapted its use here to see if it could be used as a parent-report measure for at-risk infants, thus the IBSE that is referred to throughout this thesis is a parent version.

The Ages and Stages Questionnaire. Filipek (2000) recommended the use of the ASQ 2nd edition (Bricker & Squires, 1999) (see example of 6 month questionnaire: Appendix C) in the American Academy of Neurology and the Child Neurology Society (AANCNS) practice parameter report. The ASQ is a validated parental interview (Bricker & Squires, 1999) that monitors an infant's development. The ASQ was administered every 2 months through a telephone interview, coinciding with the age sequence of the ASQ. The ASQ has 6 subscales: I. Communication, II. Gross motor, III. Fine motor, IV. Problem solving, V. Personal-social, and VI. Overall. This measure was used in the telephone interviews for the prospective study, and was not directly administered in this study, but the responses parents provided were used in data analyses.

Analyses

Internal Consistency. Internal consistency determines whether the items in a scale are homogeneous; a scale is internally consistent if the items in that scale are highly correlated, showing that all items measure the same thing (DeVellis, 1991). It is closely related to the number of items in the scale, and lack of items is one of the main reasons for a low alpha level (Nunnally & Bernstein, 1994). This was not anticipated to be a problem in this study, as both the POC and IBSE have a sufficient number of items (the POC has 61 while the IBSE has 33).

In order to measure internal consistency, we used Cronbach's alpha, as it has been suggested that it is the best way to measure internal consistency when using a scale that includes Likert items (Janda, 1998). In addition, alpha provides an accepted estimate of reliability (Nunnally & Bernstein,

1994), and is the most widely used measure of reliability (Aron & Aron, 1999). We also measured internal consistency using split-half reliability. This reliability measure correlates the average score on half of the items on the questionnaire to the average score on the other half (Aron & Aron, 1999). Inconsistencies that are reflected in the two test scores likely reflect an inconsistency in the test itself because the test is only administered once, thus minimizing the chances that carry-over effects, reactivity effects, and changes over time would affect the scores (Murphy & Davidshofer, 2001). The odd-even split was used as this ensured that equal numbers of items from the beginning, middle and end appear in both halves (Murphy & Davidshofer, 2001). We calculated the POC and IBSE internal consistency using SPSS version 10.

Test-Retest Reliability. Test-retest reliability measures the correlation of at least two tests administered to the same people on different occasions (Aron & Aron, 1999; Janda, 1998). If the variables should be stable over time, then a reliable measure of the variables should give the same measure at different points in time (DeVellis, 1991; Graziano & Raulin, 2000). The scores of different test administrations must remain consistent over time in order to have confidence in them (Kline, 1986). In order to measure this, we correlated the one-month test-retest scores from the POC, as this method is most often quantified with the correlation coefficient (Graziano & Raulin, 2000). POC test-retest reliability was calculated and correlations were obtained across one-month intervals when the child was 3-4 months, 6-7, 9-10, 12-13, 15-16, 18-19, 21-22 and 23-24 months old. IBSE test-retest reliability was not calculated as the test was only given every 2 months and there was an insufficient sample size for this (there was no n greater than 11).

Construct validity. Construct validity determines whether the scores of a particular test relate well to the construct it is addressing (DeVellis, 1991; Graziano & Raulin, 2000; Murphy & Davidshofer, 2001). Murphy and Davidshofer (2001) state “the stronger the match between the expected correlations and the actual correlations between test scores and behavior measures, the

stronger the evidence of construct validity” (p.159). We addressed two types of construct validity, convergent and discriminant. Convergent validity is the correlation between two measures that are expected to be correlated (DeVellis, 1991; Janda, 1998) – the higher the correlation, the better the convergent validity. Discriminant validity is defined as the absence of correlations between measures that are unrelated to the construct being measured (DeVellis, 1991; Janda, 1998). In order to measure convergent validity, we correlated the POC and IBSE with each other and each with the ASQ communication and social subscales (because these two skills are considered primary deficits in autism). Divergent validity was correlated using the POC and IBSE against the ASQ gross and fine motor subscale that would not be expected to show as strong a relationship.

The above analyses were all done through analyzing data that was already collected. It was entered into SPSS, version 10.0 and the necessary calculations to obtain internal consistency, test-retest reliability, interrater reliability as well as construct and discriminant validity were run.

Predictive validity. In order to measure the predictive validity of the POC, we identified the infants followed in the ASD-CARC prospective study up to age 3 who did and did not receive an ASD diagnosis (through information of a diagnosis from the prospective study). Using an independent t-test, we compared the mean POC total scores, of all POC’s given up to and including 12 months of age, of the seven diagnosed children to seven children who were not diagnosed, matched (as closely as possible) on gender and the age of the first and last POC. I hypothesized that those children who received a diagnosis would have higher POC scores than those who did not receive a diagnosis.

Results

The analyses of the POC and IBSE demonstrated acceptable reliability and validity of each measure. *N* is 80 for all analyses unless otherwise noted.

POC and IBSE Internal Consistency. Correlations were calculated for Cronbach's alpha as well as split-half reliability measures: The POC Cronbach's ($n = 35$) *alpha* was .9 and the POC split-half reliability was $r = .75$. This indicates that throughout the measure, the questions are all addressing the same construct. The IBSE Cronbach's alpha ($n = 25$) was $r = .9$ and the IBSE split-half reliability was $r = .88$, indicating, as above that the IBSE is measuring the same construct throughout.

POC Test-Retest Reliability. One-month test-retest total scores of the POC when the child was 3-4, 6-7, 9-10 and 12-13, 15-16, 18-19, 21-22, and 23-24 months old were calculated separately. These ranges were chosen to sample across the first 2-years of life and where the most data were available. The POC test-retest reliabilities were: 3-4 months, $r = .94$ ($n = 34$); 6-7 months, $r = .98$ ($n = 54$); 9-10 months, $r = .83$ ($n = 58$); 12-13 months, $r = .68$ ($n = 71$); 15-16 months, $r = .86$ ($n = 60$); 18-19 months, $r = .98$ ($n = 58$); 21-22 months, $r = .89$ ($n = 52$); and 23-24 months, $r = .99$ ($n = 40$). These results suggest that the POC is highly stable over one-month intervals, over the first 24 months of life, although the reliability between 12-13 months was lower than the others.

Table 2

Test-Retest Reliability for the POC

Age (months)	Reliability (r)
3-4 ($n = 34$)	.94
6-7 ($n = 54$)	.98
9-10 ($n = 58$)	.83
12-13 ($n = 71$)	.68
15-16 ($n = 60$)	.86
18-19 ($n = 58$)	.98

21-22 ($n = 52$)	.89
23-24 ($n = 40$)	.99

POC and IBSE Construct Validity. POC and IBSE convergent validity yielded a $r = .77$, $p < .01$, ($n = 35$) when they were correlated with each other, which suggests that both measures were measuring the same construct. As predicted the POC was moderately negatively correlated with the ASQ social domain, $r = -.44$, $p < .01$, but the IBSE correlation with the ASQ social domain was weak, $r = -.21$. Both the POC and IBSE were moderately correlated with the ASQ communication domain with an r 's = $-.55$ and $-.45$, respectively, $p < .01$.

In order to determine divergent validity, each measure was correlated with the ASQ gross and fine motor subscale. As predicted, the POC and IBSE were not significantly correlated with the gross motor subscale, r 's = $-.20$ and $-.18$ respectively. However the POC and IBSE were significantly negatively correlated with the ASQ fine motor subscale, r 's = $-.53$ and $-.58$ respectively ($p < .01$). This shows that the POC is measuring a different concept than the ASQ gross motor scale, but there may be some moderate overlap between early signs of ASD and fine motor abilities.

Predictive Validity. There were 7 infants at age 3 years who had been independently diagnosed with an ASD. Each diagnosed infant was matched with another child, who had not been diagnosed by age 3 years on gender and age on first and last POC (within one month). Thus, in each group, diagnosed infants $n = 7$, and undiagnosed infants $n = 7$.

The mean age of the first POC for the diagnosed infants was 4.57 months ($SD = 2.29$) and 3.86 months ($SD = 1.68$) for the undiagnosed infants. The mean age of their last POC for the diagnosed infants was 14.86 months ($SD = 8.75$) and 19 months ($SD = 8.91$) for the undiagnosed infants. The mean total number of POC's for the diagnosed infants was 7.86 ($SD = 3.29$) and 8.71 ($SD = 3.95$) for the undiagnosed group. The mean total number of POC's up to 12 months was 5.00

($SD = 1.41$) for the diagnosed group, and 4.14 ($SD = 3.29$) for the undiagnosed group. There were no significant differences in any of these measures.

Predictive validity of the POC was evaluated by comparing the mean number of elevated POC items (a score of 3 or greater on any item) for the diagnosed infants and matched undiagnosed infants. The mean number of elevated items on all POC's in the diagnosed group was 4.74 ($SD = 6.16$), while the mean number of elevated POC items for the undiagnosed infants was .55 ($SD = .52$). One-tailed tests were used because an a priori prediction was made that diagnosed children would have higher POC's than the undiagnosed children. A test of independent samples showed that the diagnosed infants had significantly more elevated POC items across all POC's, $t(12) = 1.79, p < .05$ (one-tailed). Looking at POC's just up to 12 months of age, the mean number of elevated items for the diagnosed infants was 4.59 ($SD = 6.20$), and .55 ($SD = .52$) for the undiagnosed group. An independent t -test conducted on the mean number of elevated POC items only up to 12 months of age was $t(12) = 1.72, p < .06$ (one-tailed). Thus, the analyses of predictive validity of the POC suggests that it may differentiate at risk infants who eventually receive an ASD diagnosis from similar at risk infants who do not receive an ASD diagnosis by 3 years of age.

Discussion

Study 1 has shown that both the POC and IBSE demonstrate acceptable reliability and validity, shown through a variety of analyses. They each had acceptable internal consistency as demonstrated with Cronbach's *alpha* and split-half reliability, and the POC showed acceptable one-month test-retest reliability across different age ranges within the first 24 months of life. Both the POC and IBSE showed acceptable convergent validity, despite the IBSE and the social domain of the ASQ, while they also showed divergent validity with the ASQ gross motor subscales, as expected.

Perhaps the most important finding of Study 1 was the evidence supporting the predictive validity of the POC. Despite the sample of diagnosed infants only being seven, the number of

elevated POC items over the first 24 months differentiated children who eventually were diagnosed with ASD from those that were not; the predictive results for the first 12 months of the POC approached significance. The possibility that a parent-report measure may be able to detect infants (even in the first year of life) at higher risk for developing ASD is very exciting and warrants further study. Further research should also look at which POC items or subscales are most predictive of subsequent diagnosis.

Another interesting finding from this study was the correlation between fine motor skills and early signs of autism as indicated through the correlation between the ASQ fine motor subscale and the POC. There is increasing evidence that children with autism have delays in fine motor functioning (Berkeley, Zittel, Pitney, & Nichols, 2001; Hauck and Dewey, 2001), thus starting to explain the unexpected finding.

Future research is needed with a larger sample size to verify the findings and extend these preliminary findings. The IBSE test-retest reliability and predictive validity need to be established, as well as interrater reliability on the POC and IBSE. For instance, the mother and father could complete the POC independently and their scores would be compared. Likewise, the videotapes sent in by the families could be scored by “blind” autism experts using the POC to compare with the parents’ ratings of the child at the same age, thus establishing external reliability of the measure. More research is needed on the predictive validity of the POC, such as examining which POC subscales and items are most predictive of future diagnoses of ASD. A larger sample size is needed to determine the predictive strength of the POC’s given in the first year of life. Another area that needs to be addressed in future research is external criterion validity, as all these results were based on parent-report.

As we have demonstrated acceptable reliability and validity of the POC (and to a lesser extent the IBSE), we used parent report measures to detect infants from the sample who were showing problems indicative of ASD and looked at what services they received.

Study 2 – Parent-selected interventions for infants at risk of ASD and affected siblings

Autism Interventions

There are probably thousands of interventions that are currently being used with children who have ASD. The more popular interventions include floor time, gentle teaching, facilitated communication, sensory integration, special diets, vitamin therapies, and secretin, among many others (see Table 3). The only one with empirical support is Early Intensive Behavioral Intervention (EIBI), initiated by Ivar Lovaas. Lovaas (1987) was the first person to demonstrate effects of teaching autistic children in a “special, intense, and comprehensive learning environment” (p.4). EIBI is a program in which young children (aged 2 until 5 years) receive one-on-one intensive intervention for up to 40 hours per week. There is a focus on discrimination learning, operant conditioning, data collection, and following written programs. Early in treatment, there is reliance on one-to-one training and discrete trial training in their own home to maximize success. As the child progresses, focus is shifted to more naturalized environments such as preschool and playgroups. Targets range from imitation and establishing appropriate toy play in the first year, to teaching appropriate emotions, observational learning and preacademic tasks in the third year; targets are developmentally sequenced based on each child’s individual needs. Mainstreaming the children into public kindergarten is the goal.

Lovaas (1987) was successful in mainstreaming 9 of 19 participants from the experimental group (47%) into kindergarten as “best outcome” children. “Best outcome” referred to children who achieved an average IQ (mean = 99), along with no aides. Only 10% (2 of 19 subjects) of the treatment group had to be placed into a special education class for autism or mental retardation. The fact that there was no randomization was a large limitation, but in a follow-up of the study children 6 years later, McEachin, Smith and Lovaas (1993) showed that the children who had the best early

outcomes had the same (regular) school placement, had maintained their gains in intellectual functioning, and showed more adaptive and fewer maladaptive behaviors than the control group.

Table 3

Some common Interventions used in treating Autism Spectrum Disorders

Intervention	Purpose/Rationale	Authors	Methods	Research
Early Intensive Behavioral Intervention	To provide children with autism the skills necessary to succeed in society	Lovaas, 1987; McEachin, Smith & Lovaas, 1993	Intensive one on one discrete trial teaching	The only <i>empirically validated</i> intervention; McEachin, Smith & Lovaas, 1993 did a follow-up of Lovaas 1987 study which showed maintenance of results
Special Diets	Improving the behavioral and cognitive functioning of people with autism through the removal of casein and/or gluten from their diets	Knivsberg, Reichelt, Hoiem, & Nodland, 2002; Whiteley, Rodgers, Savary, & Shattock, 1999; Bowers,	Exclusion of casein and/or gluten from the diet	Studies have shown some improvement in autistic behaviors (Knivsberg, et al., 2002; Whiteley, et al., 1999) yet others have mixed results (Bowers, 2002)

2002

Secretin	Injecting children with autism with the hormone secretin in the hopes of altering the behavior and core features of autism	Horvath, 1998;	Injections or ointment	Double-blind, randomized, crossover design have indicated the effects of secretin are not significantly different than the use of a placebo (Ratliff-Schaub, Carey, Reeves, & Rogers, 2005); and that there are no clinically significant or sustained gains in the behavior or core features of autism (Handen & Hofkosh, 2005)
Vitamin Therapy	“The treatment of mental disease by the provision of optimum concentrations of substances normally found in the human body” (Pauling, 1968 as	Pauling, 1968 as cited in Pfeiffer et al., 1995	Combination of vitamin B6 and magnesium	Little research could be found; Pfeiffer et al., 1995, supported the research through a literature review; Page (2000) contends that efficacy is dependent on which vitamin is used

cited in Pfeiffer,
Norton, Nelson
and Shott, 1995)

Sensory Integration	Aims to help organize sensations from the body and environment so to act more effectively in the environment	Ayers, 1979	Delivered in a one on one setting in which an occupational therapist and the child engage in various activities children enjoy such as massage, swinging, and rocking (Green, 1996)	Subject of little research; Smith, Mruzek & Mozingo (2005) state that research has shown it to be “ineffective and...unvalidated” (p.345) as shown in Green, 1996, studies that have been conducted tend to portray its ineffectiveness
Facilitated Communication	To help autistic clients to convey their thoughts and feelings, which they have	Biklen, 1990, 1992a; Biklen, Saha & Kliwer,	Involves client who uses a typewriter or alphabet board to point at	Very controversial in research; originators claim effectiveness based on qualitative analysis (e.g. Biklen, 1990); empirical

previously been 1995, as letters to research: facilitated
 unable to convey cited in convey their communication has “not
 Jacobson, thoughts while been verified in numerous
 Foxx, & a facilitator peer-reviewed journals”
 Mulick, holds their (p.364) (Jacobson, Foxx,
 2005 arm in order & Mulick, 2005); much
 to keep it research supports that the
 stabilized, source of communication
 help point, is the facilitator
 pull back arm
 after pointing
 and to offer
 support

Floor Time Metz, Mulick & Greenspan Done through Little support for this
 Butter (2005) & Weider, direct one on intervention and few
 describe this 1998; one studies have been
 approach as Greenspan, interactions published; Metz, Mulick
 helping the child 2000; and help & Butter (2005) mention
 to master, in Greenspan, parents only one study supporting
 developmental 2001 become more its efficacy, but it is
 sequence, six effective descriptive and not
 foundational teachers; experimental; a search of
 milestones in interactions psychology databases
 order they have include play PsycArticles and

the capacity for environments, PsycINFO yielded no communication, child-led results thinking and interactions, emotional coping and tailoring (p.254); help the interactions to parents to become the child's organizer in their individual child's life style (p.254)

Gentle Teaching	Nonviolent approach to teach individuals to feel safe, engaged, unconditionally loved and to feel love towards others (Cullen & Mudford, 426); there is currently no clear description of gentle teaching, its processes or intended	McGee, 1985a, b, c; McGee, Menolascin, Hobbs & Menousek, 1987; McGee & Menolascin, 1991; all as cited in Cullen & Mudford, 2005	Emphasis on the nature of interactions between client and caregiver; seen as type of bonding; how this is done was not effectively described anywhere	Lack of research is again apparent; Cullen & Mudford (2005) show that what has been done has shown gentle teaching as not effective (e.g. Jordan, Singh, & Repp, 1989; Barrera & Teodoro, 1990; Cullen & Mappin, 1998)
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outcomes (Cullen
& Mudford,
2005)

Adapted from Scheuermann & Webber, 2002

Green, Brennan, and Fein (2002) conducted a single-case EIBI study, which also lends credibility to the use of this intervention with infants. The participant was a girl aged 1 year and 2 months, diagnosed unusually early with autism. She went through a program designed by the second author, similar to that of Lovaas, until she was 4 years 5 months old. Examples of the skills worked on were: readiness, imitation, preacademic and social skills among others. The program had her going to increasingly integrated schools (preschools) throughout her program for longer and longer periods of time, with a one-on-one aide. As a result of the treatment program, the child was enrolled in a regular public school kindergarten with no diagnosis and no aides.

Smith and Antolovich (2000) studied supplemental interventions for children in Lovaas' EIBI treatment. They did this through mail-out surveys, which identified common supplemental interventions for children with autism, as well as a rating of the impact of each intervention: positive, negative, or neutral. The most popular supplemental interventions that parents identified were speech-language therapy, megadoses of B6 with magnesium, sensory integration therapy, and elimination diets. They were generally rated as beneficial (50%) or neutral (38%).

Smith and Antolovich (2000) then followed up that study by setting up telephone interviews with primary caregivers of children who were receiving consultation from the primary author's EIBI treatment site. In the interview, parents were asked about the four most popular interventions listed above, and such questions as the start and stop date, specific techniques used, source that parents heard about it, as well as the features of the intervention that contributed to their decision to implement it and what problems their child had to start the intervention at that time. It was

determined from this series of questions that positive effects were reported, that speech therapy generally began prior to EIBI in contrast to the other 3 interventions that started after EIBI. How parents heard about the intervention and the factors contributing to starting the intervention varied depending on what intervention it was (e.g. found out about speech at the time of diagnosis from professionals involved in the diagnosis, versus finding out about diets from other parents).

Effectiveness of Parent-Managed Programs

There are a number of characteristics of intensive behavioral programs, and they differ whether it is a parent-based program or a program that is run by professionals. Mudford, Martin, Eikeseth, and Bibby (2001), highlighted some characteristics of United Kingdom based parent-managed behavioral treatments, and illustrated some problems with them. Parent-managed programs are becoming increasingly prevalent as there is a current shortage of certified EIBI workers that can provide Lovaas' therapy (Mudford et al., 2001). Parents are thus taking things into their own hands, and through the use of consultants, devise their own program and then run it out of their homes. Mudford et al. (2001) as well as Bibby, Eikeseth, Martin, Mudford, and Reeves (2002) wanted to see if these parent-run programs would be as successful as the Lovaas program. It was determined in both studies that parent-run EIBI programs may not be as successful as when being run in a center, as parents may not follow the protocols as rigorously.

EIBI Drawbacks

A large drawback to EIBI is the cost, thus possibly limiting the number and types of families who participate in them, if they cannot get outside funding. Jacobson, Mulick and Green (1998) stated that although expensive - approximately \$60,000 per child per year for 40 hours per week – EIBI results in considerable savings in the long run by reducing life-long need for specialized (and expensive) supports for some children. Jacobson and Mulick (2000) state the importance of being sure the benefits of EIBI exceed the costs, and through saving money on future supports (e.g.,

interventions throughout adulthood), it obviously does. Jacobson et al. (1998) justify the upfront expense of EIBI based on potential long-term cost-benefit and the absence of other evidence-based interventions.

EIBI Supports

Supports (for example, support groups and family support) in running an EIBI program are imperative. Hastings (2003) has shown that when there is large amount of support available, siblings of the children receiving EIBI adjusted better, as evidenced by their score on the Autism Behavior Checklist, which was used as an index of autistic symptomology in autistic children. Hastings (2003) also showed there was no negative effect on sibling's adjustment, though these siblings were not necessarily better adjusted than other children in the country. Hastings and Symes (2002) have shown that "therapists in less supportive or cohesive ABA teams, working with children with more severe symptoms of autism, and who are also experiencing high levels of stress will have less of a belief in their efficacy as a therapist" (p.339). Thus, the more severe the child and the more support the therapists have, the more efficacious the therapists will feel. Moes (2002) reported that when family components are integrated into the intervention, this also helped with the family's perception of the therapy, and that self-reports from the parents in regards to EIBI showed a good sustainability within the family life. This is important as it affects the parent's perceptions of EIBI and its effectiveness.

Hastings and Johnson (2001) reported stress levels of parents involved in the EIBI program, and found that these levels were not any higher than those of other parents of children with autism who were not involved with the EIBI program, thus demonstrating that the program does not place undue stress on parents (or, in fact, that stress is ameliorated by other factors such as program efficacy), and in fact, lowers stress the longer that their child is involved in EIBI. This is imperative for programs such as EIBI as parents are already concerned about their child's development;

implementing programs such as EIBI should not put undue stress on parents, which has been shown to be the case. Other than social supports, other factors that were associated with lower stress levels included parental adaptive coping strategies, and their beliefs about the efficacy of the intervention.

Justification and Research Questions

Due to the lack of research with infants with and at risk for autism in their first year, this study is designed to assess parent-selected interventions for their infants who are genetically at risk for ASD, as well as the choices of services that they are providing to their older children who have been diagnosed. Once we looked at these services, we could determine which ones worked the best according to parents and see which ones minimized symptoms to the greatest degree.

This study describes interventions parents choose to implement for their at risk infants (prior to diagnosis), as well as for their affected children. Using a service questionnaire, we looked at which interventions parents utilized, whether the interventions were evidenced-based, whether the parents felt those interventions helped or not, and whether there were any side effects. I also asked whether these interventions decreased parental stress and improved parents' self-efficacy in dealing with their children and their behaviors.

Research Question. The research question was what interventions do parents use for their at-risk infants and their affected siblings? We were interested to find out about all the interventions and services the children are receiving, what the parents thought of the interventions, and whether the interventions change parental stress and self-efficacy, i.e., whether intervention helped them to deal better with their children's presenting problems. The last question we looked at was the prevalence of non-empirically validated services being used with the diagnosed older siblings.

Method

Participants

The subjects in this study were families recruited from the larger prospective study. All families had at least 2 children; the older child had a diagnosis of autism, thus the infant was at a higher risk for developing autism as well (high-risk infants). I looked specifically at 23 families in which parents had reported (on the POC, IBSE, and/or during the ASD-CARC prospective study interview) that the infants were showing developmental and/or behavior problems that may be indicative of early signs of ASD. Some of these families had interventions and some had not.

Materials

There were six primary measures that were used. They include the Family Information Questionnaire, the Service questionnaire, Parent Observation Checklist (POC), the Infant Behavior Summary Evaluation (IBSE), and the Ages & Stages Questionnaire (ASQ).

Family Information Questionnaire. This questionnaire (Appendix D) provided us with general demographic information about the families. Questions such as family income, health, education and age were asked in this questionnaire for all members of the immediate family.

Service Questionnaire. This questionnaire (Appendix E) is adapted from one that has been used with over 200 young children with developmental delay (Feldman, 2006). The questionnaire was used to assess the type and number of interventions that the infant was receiving, to what extent the parents were involved in the intervention, how satisfied they were with the intervention and to what extent they thought each intervention helped their child. The questionnaire covered everything from birth to current, and start and end dates (if relevant) were recorded. In order to determine answers to the above questions, each service had 5 questions that corresponded to it, including level of parental involvement, rated on a 7-point Likert scale with 7 being the highest level of involvement and 1 being the lowest. Also included was structure, the need/importance of the service (i.e., how

much the parent wanted it), satisfaction and effectiveness. They were all rated on similar 7-point Likert scales. In addition to these measures, we also asked the parents a variety of open-ended questions relating to the interventions they provided their infant. These questions included ones such as asking what specific interventions they hoped to receive in the future for their child, how they found out about the current interventions that they were using, why they chose these particular interventions as opposed to others, how involved they are in their child's therapy, and whether or not there have been any side effects. Also of interest was how the parents perceived these interventions as helping them to deal with stress and whether the interventions were seen as increasing parental self-efficacy. These were addressed through retrospective questions at the end of the interview, and were also measured by a similar 7-point Likert scale.

Popular treatments for young children with autism were listed and there was room for parents to add others. The services listed included sensory integration, vitamin therapy, speech-language training and behavioral interventions, and the (evidenced-based) advice that the interviewer from the prospective study had given parents during telephone interviews was also included as a possible service. The same service questionnaire was also completed about the services received for their older child, already diagnosed with ASD.

Procedure

Interviews. As previously mentioned, parents of the high-risk infants were being interviewed every 2 months, by an experienced, specially trained interviewer. During this interview, the interviewer noted concerns and discussed them with the parents while administering the POC (if the parent had not already filled it out online), the ASQ and the IBSE. If parents requested, the interviewer, who was experienced in autism, provided some advice, and sometimes sent some written materials from evidenced-based intervention manuals.

For Study 2, I contacted the parents, identified by the interviewer, who had reported that their infant had problems. I sent a letter of invitation and consent form (see Appendix F). After obtaining consent, I administered the family information questionnaire and the service questionnaire over the phone.

Design

For each participant, I recorded parent responses on the Service Questionnaire. I then averaged each answer to the questions of parental involvement, structure, need, satisfaction and effectiveness. I also totaled how many children were receiving each service in order to determine the most popular services. Parental levels of stress and competence were also averaged. These calculations were each done separately for infants and the diagnosed group. Only scores where the parents reported using a service were used.

Results

Parents employed a variety of services for both their children, ranging from empirically validated services, such as EIBI, to non-empirically validated ones such as diet therapy, vitamin therapy and hippotherapy. See Table 3 for a complete list of all services parents were providing their children, rank ordered in terms of the most popular service for the affected child. The most popular services for the infant were advice from the prospective study interviewer ($n = 11$), followed by speech therapy and daycare ($n = 6$), and then diet and vitamin therapy ($n = 4$). Overall, infants received an average of 2.3 services (range 0-7), while their affected siblings received an average of 7.5 services (range 3-12).

Table 4

Most Popular Services Selected by Parents (n=23)

Service	Affected	Infant
Special Needs Worker	19	1
Behavioral Interventions	16	2
Speech-Language Therapy	16	6
Regular Daycare	14	6
Diet Therapy	13	4
Vitamin Therapy	12	4
Occupational Therapy	12	2
Herbal Remedies	11	2
Specialized Preschool	11	2
Sensory Integration	10	3
Prescription Medication	7	3
Advice from ASD-CARC	5	11
Horseback Riding (Hippotherapy)	5	0
Secretin	3	0
Physiotherapy	3	1
Day Camp (Special Needs)	2	0
Music Therapy	2	1
Floor Time	2	1
Chiropractor	1	1

Developmental Therapy	1	1
MB-12 Injections	1	0
Swimming	1	0
Assisted Technology	1	0
Auditory Integration	1	0
RDI	1	0
Special Education Program	1	0
Respite	1	0
Children's Health and Development	0	1
Home Visit – Eating Problems	0	1
Therapeutic Listening	0	1

An interesting finding was the number of services that parents were implementing that were not empirically validated. We decided to look at the number of affected children who were receiving EIBI only as a service versus those affected children receiving EIBI plus three or more eclectic services and those receiving only eclectic services. We found that there were *no* children receiving only EIBI, whereas 16 (69.6%) were receiving EIBI plus at least three eclectic treatments (range 3 to 11), and 7 (30.4%) children were receiving *only* eclectic treatments (range 3 to 9).

The rest of the service questionnaire was designed to look at parent involvement in the therapy, structure, need/importance, satisfaction and effectiveness. Each was averaged according to which group they were in (infant or affected child). For the infant group, on a scale of 1-7, where 1 is the lowest and 7 is the highest, mean parent involvement was 6.3, structure was 5.8, need/importance was 6.1, satisfaction was 5.9 and effectiveness was 5.7 (see Table 5).

Table 5

Infant Results

Dimension (<i>n</i> = 54)	Mean
Parent Involvement	6.3
Structure	5.8
Need/Importance	6.1
Satisfaction	5.9
Effectiveness	5.7

The mean values for the affected child were similar and were, for parental involvement, 6.3, for structure 5.6, need/importance 6.4, satisfaction 5.3 and effectiveness 5.0 (see Table 6). The above results indicate that parents report that they are involved, moderately satisfied, and think that services are reasonably effective.

Table 6

Affected Siblings Results

Dimension (<i>n</i> = 173)	Mean
Parent Involvement	6.3
Structure	5.6
Need/Importance	6.4
Satisfaction	5.3
Effectiveness	5.0

We were also interested in how the parents' stress levels and their parental competence was affected once they started to implement services with their children, and this question was asked about both the infants and the affected child. The infants' parents reported on a scale of 1 to 7 (7 is greatly decreased and 4 is no change) that, on average, their stress levels were 4.8, indicating that by providing services to their infants their stress levels remained unchanged. Parental competence change score was 5.2, on a similar scale of 1-7 (7 is greatly increased and 4 is no change), indicating a slight increase in feelings of competence when services were implemented.

When referring to their affected child, parents reported that their stress levels to be 3.9, while their parental competence was 5.5, on the same scales as described above. This indicates that although stress levels have stayed more or less the same, providing services to their affected child somewhat increased their feelings of competence.

Discussion

The results of this study show that parents are providing services to their infants when signs of autism become evident at an average of 2.3 services per infant. The services that they are providing are generally non-empirically based. This finding extends the study by Smith and Anotolovich (2000) who showed the frequent reliance on similar non-empirically validated treatments with children diagnosed with ASD. This study found similar use of non-validated interventions not only for affected children, but also their at risk infant siblings. An interesting finding was that no affected children received only empirically validated treatments; in all cases, empirically validated treatments were combined with non-validated ones, or only non-validated treatments were used. Despite the use of non-validated treatments in this study, parents reported that the services were generally effective, and that they were moderately satisfied and involved in them, although, based on self-report, parental stress and competence were minimally affected by these interventions.

An important implication of this study lies with current research that is being done with evaluating EIBI treatments. This is due to the results of this study that shows that although EIBI is being used with those children who have been diagnosed with autism, it is not generally used by itself. This could affect results of the studies evaluating EIBI as these other treatments that are being used may conflict with EIBI and the effects that EIBI may have on the child.

The results of Study 2 were very interesting, but there are some limitations to keep in mind. The first is that these were all parent-report measures. There was no independent verification of the use, nature and effectiveness of the services the parents described to the interviewer. Reports of intervention effectiveness may reflect the parents' wishful thinking that their child's symptoms would change with treatment. This was also a limitation in Smith and Antolovich (2000) in which they state that parental report may have resulted in unreliable information, though there is some evidence to support parent report by Baranek, Zwaigenbaum, Reznick, Watson, Crais, et al. (2006). Baranek et al. (2006) showed that parent report and observational measures at 12 months of age are modestly correlated, lending some important credibility to parent report measures. Another major limitation to this study is that these families may not be representative of all families in similar situations. Because of a lack of response to the family information questionnaire, it cannot be determined how representative they are. Future research should try different methods of completing the family information questionnaire, perhaps as part of the telephone interview instead of mailing them out.

There are a few areas that future research should concentrate on, such as replicating the study with a larger sample size. It would also be important to set up a prevention study with children genetically at risk for autism. This can be done by identifying at risk infants and starting interventions with them right away instead of waiting for symptoms to present.

Due to the results that arose, it can be seen that parents are implementing many interventions with their children, though they are generally only minimally satisfied with them. Smith and Antolovich (2000), indicate that because of the minimal effectiveness of supplemental intervention, among other reasons, parents and professionals need to be further educated on how to determine if interventions are scientifically sound. They go on to recommend a few ways to do this, including reporting findings in the media of these interventions, rebutting credulous stories, and trying to influence the policies of funding agencies so that these agencies are not funding treatments that are not scientifically sound (Smith & Antolovich, 2000). Exploring these recommendations from Smith and Antolovich are imperative to the future of children with autism, as they need to receive the most effective treatments.

General Discussion

In Study 1, we found support for an initial validation of parent report instruments that can be used to track early features of ASD in at-risk infants. Such a low-cost instrument is valuable in identifying children who are beginning to develop ASD so that further assessment could be conducted and evidence-based intervention can be started as early as possible. Very early intervention may prevent an autism diagnosis or at least lead to better outcomes than starting after 2 years of age. The POC is a promising instrument that can begin to differentiate children who will be diagnosed in the future versus those who will not be.

Study 2 examined what interventions parents chose for their at risk infants (who are beginning to show developmental and/or behavioral problems) and their affected siblings. Parents reported being moderately involved and satisfied in the services their children are receiving. The parents also reported that they felt the services were somewhat effective in reducing autistic symptoms.

This study adds to the literature on infants at risk for ASD. We are beginning to design a valid, low-cost instrument to track autistic symptoms in at risk infants and identify those likely to eventually be diagnosed with ASD. This finding is important as it may eventually lead to more children being identified and receiving effective (very) early intervention as soon as possible. For children who may be developing autism, this preventative or very early intervention can be the difference between severe disability requiring extraordinary life-long supports versus living their lives to the fullest.

References

- Adrien, J., Barthelemy, C., Perrot, A., Roux, S., Lenoir, P., Hameury, L. & Sauvage, D. (1992).
Validity and reliability of the Infant Behavioral Summarized Evaluation (IBSE). *Journal of Autism & Developmental Disorders*, 22, 375-394.
- Adrien, J-L., Roux, S., Couturier, G., Malvy, J., Guerin, P., Debuly, S, et al. (2001). Towards a few functional assessment of autistic dysfunction in children with developmental disorders: The behavior function inventory. *Autism*, 5, 249-264.
- Adrien, J. L., Lenoir, P., Martineau, J., Perrot, A., Hameury, L., Larmande, C. & Sauvage, D. (1993).
'Blind Ratings of Early Symptoms of Autism Based upon Family Home Movies. *Academy of Child and Adolescent Psychiatry*, 32, 617-26.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual*. Fourth Edition, Text Revision. Washington, DC: Authors
- Aron, A., & Aron, E.N. (1999). *Statistics for psychology (2nd Ed.)*. Upper Saddle River, NJ: Prentice-Hall, Inc.
- Ayers, J.A. (1979). *Sensory Integration and the Child*. Los Angeles, CA: Western Psychological Services.
- Baranek, G.T. (1999). Autism during infancy: A retrospective video analysis of sensory-motor and social behaviors at 9-12 months of age. *Journal of Autism and Developmental Disorders*, 29 (3), 213-224.
- Baranek, G.T., Zwaigenbaum, L., Reznick, J.S., Watson, L.R., Crais, E.R., Bryson, S. (2006, June).
Comparison of the first year inventory and the autism observation scale for infants in 12-month old siblings of children with autism (abstract). Paper presented at the International Meeting for Autism Research, Montreal.

- Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months? The needle in the haystack and the CHAT. *The British Journal of Psychiatry*, 161, 839-843.
- Baron-Cohen, S., Cox, A., Baird, G., Swettenham, J., Nightingale, N., Morgan, K. et al. (1996). Psychological markers in the detection of autism in infancy in a large population. *The British Journal of Psychiatry*, 168, 158-163.
- Baron-Cohen, S., Wheelwright, S., Cox, A., Baird, G., Charman, T., Swettenham, J., Drew, A., & Doehring, P. (2000). The early identification of autism: The checklist for autism in toddlers (CHAT). *Journal of the Royal Society of Medicine*, 93, 521-525.
- Berkeley, S.L., Zittel, L.L., Pitney, L.V., & Nichols, S.E. (2001). Locomotor and object control skills of children diagnosed with autism. *Adapted Physical Activity Quarterly*, 18, 405-416.
- Bibby, P., Eikeseth, S., Martin, N.T., Mudford, O.C., & Reeves, D. (2002). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disorders*, 23(1), 81-104.
- Biklen, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60(3), 291-314.
- Bowers, L. (2002). An audit of referrals of children with autism spectrum disorders to the dietetic service. *Journal of Human Nutrition and Dietetics*, 15(2), 141-144.
- Brian, J.A., Zwaigenbaum, L., Bryson, S.E., Roberts, W., Szatmari, P., Smith, I. (2006, June). *Predictive validity of the autism observation scale for infants* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.
- Bricker, D. & Squires, J. (1999). *The Ages and Stages Questionnaires*. Paul H. Brookes, Baltimore, MD.
- Chudley, A.E., Tackels, D.C., Lubs, H.A., Arena, J.F., Stoeber, W.P., Kovnats, S., Stevenson, R.E., & Schwartz, C.E. (1999). X-linked mental retardation with seizures, hypogammaglobulinemia,

and progressive gait disturbance is regionally mapped between xq21.33 and xq23. *American Journal of Medical Genetics*, 85, 255-262.

Cox, A., Klein, K., Charman, T., Baird, G., Baron-Cohen, S., Swettenham, J., et al. (1999). Autism spectrum disorders at 20 and 42 months of age: Stability of clinical and ADI-R diagnosis.

Journal of Child Psychology and Psychiatry, 40(5), 719-732.

Crais, E.R., Watson, L.R., Baranek, G.T., Boyd, B.A., Miller, H.L., & Wilson, K.P. (2006, June).

Developmental patterns of gesture use in infants with autism spectrum disorders (abstract).

Paper presented at the International Meeting for Autism Research, Montreal.

Croen, L.A., Grether, J.K., & Selvin, S. (2002). Descriptive epidemiology of autism in a California population: Who is at risk? *Journal of Autism and Developmental Disorders*, 32(3), 217-224.

Cullen, C. & Mudford, O.C. (2005). Gentle Teaching. In Jacobson, J.W., Foxx, R.M., & Mulick, J.A. (Eds.), *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice*, (pp.423-432). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.

DeVellis, R.F. (1991). *Scale development: Theory and applications*. Newbury Park: Sage Publications.

Eaves, L.C. & Ho, H.H. (2004). The very early identification of autism: Outcome to age 41/2 -5.

Journal of Autism and Developmental Disorders, 34(4), 367-378.

Eaves, L.C., Wingert, H., & Ho, H.H. (2006). Screening for autism: Agreement with diagnosis.

Autism, 10 (3), 229-242.

Fein, D., Robins, D., Liss, M., & Waterhouse, L. (2001). The nature of autism. In C., Maurice, G.

Green, & R.M., Foxx, (Eds.), *Making a Difference: Behavioral Interventions for Autism* (pp. 23-35). Austin, TX: Pro-Ed.

- Feldman, M.A. (2006, May). *Discrepancy between service needs and utilization in families of children with or at-risk for developmental delay*. Paper presented at the American Association on Mental Retardation Annual Conference, Montreal.
- Feldman, M.A , & Ward, R.A. (2001). *The Parent Observation Checklist: Identification of early symptoms of Autistic Spectrum Disorder in infants at biological risk for ASD*. Unpublished.
- Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Dawson, G., Gordon, B., Gravel, J. S., Johnson, C. P., Kallen, R. J., Levy, S. E., Minshew, N. J., Prizant, B. M., Rapin, I., Rogers, S. J., Stone, W. L., Teplin, S., Tuchman, R. F. & Volkmar, F. R. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism & Developmental Disorders*, 29, 439-84.
- Filipek, P.A, Accardo, P.J., Ashwal, S., Baranek, G.T., Cook, E. H. Jr., Dawson, G., Gordon, B., Gravel, J.S., Johnson, C.P., Kallen, R.J., Levy, S.E., Minshew, N.J., Ozonoff, S., Prizant, B.M., Rapin, I., Rogers, S.J., Stone, W.L., Teplin, S.W., Tuchman, R.F. & Volkmar, F.R. (2000). Practice parameter: Screening and diagnosis of autism: Report of the quality standards subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55, 468-479.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: An update. *Journal of Autism and Developmental Disorders*, 33(4), 365-382.
- Fombonne, E. (2005). The changing epidemiology of autism. *Journal of Applied Research in Intellectual Disabilities*, 18, 281-294.
- Gillberg, C. (1998). Chromosomal disorders and autism. *Journal of Autism and Developmental Disorders*, 28, 415-425.
- Glascoe, F.P., Foster, M., & Wolraich, M.L. (1997). An economic analysis of developmental detection methods. *Pediatrics*, 99(6), 830-837.

- Gray, K. & Tonge, B. (2001). Review article: Are there early features of autism in infants and preschool children?. *Journal of Pediatric Child Health*, 37, 221-226.
- Gray, K.M., & Tonge, B.J. (2005). Screening for autism in infants and preschool children with developmental delay. *Australian and New Zealand Journal of Psychiatry*, 39, 378-386.
- Graziano, A.M., & Raulin, M.L. (2000). *Research methods: A process of inquiry (4th Ed.)*. Needham Heights, MA: Allyn and Bacon.
- Green, G. (1996). Evaluating claims about treatments for autism. In C. Maurice, G. Green & S. Luce (Eds.). *Behavioral intervention for young children with autism: A manual for parents and professionals*. (pp. 15-28). Austin, TX: Pro-Ed, Inc.
- Green, G., Brennan, L.C., & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification*, 26(1), 69-102.
- Greenspan, S.I. (2000). Children with autism spectrum disorders: Individual differences, affect, interaction, and outcomes. *Psychoanalytic Inquiry*, 20, 675-703.
- Greenspan, S.I. (2001). The affect diathesis hypothesis: The role of emotions in the core deficit of autism and in the development of intelligence and social skills. *Journal of Developmental and Learning Disorders*, 5, 1-45.
- Greenspan, S.I. & Wieder, S. (1998). *The child with special needs: Encouraging intellectual and emotional growth*. Reading, MA: Addison-Wesley.
- Handen, B.J., & Hofkosc, D. (2005). Secretin in children with autistic disorder: A double-blind, placebo controlled study. *Journal of Developmental and Physical Disabilities*, 17, 95-106.
- Hastings, R.P. (2003). Behavioral adjustment of siblings of children with autism engaged in ABA early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, 33(2), 141-150.

- Hastings, R.P. & Johnson, E. (2001). Stress in UK families conducting home-based behavioral interventions for their young children with autism. *Journal of Autism and Developmental Disorders*, 31(3), 327-336.
- Hastings, R.P. & Symes, M.D. (2002). Early intensive behavioral intervention for children with autism: Parental therapeutic self-efficacy. *Research in Developmental Disorders*, 23(5), 332-341.
- Hauck, J.A., & Dewey, D. (2001). Hand preference and motor functioning in children with autism. *Journal of Autism and Developmental Disorders*, 31, 265-277.
- Horvath, K., Stefanatos, G., Sokolski, K.N., Watchel, R., Nabors, L., & Tildon, J.T. (1998). Improved social and language skills after secretin administration in patients with autism spectrum disorder. *Journal of the Association for Academic Minority Physicians*, 9(1), 9-15.
- Jacobson, J.W, Foxx, R.M. & Mulick, J.A. (2005). Facilitated communication. In Jacobson, J.W., Foxx, R.M., & Mulick, J.A. (Eds.), *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice*, (pp.363-383). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Jacobson, J.W. & Mulick, J.A. (2000). System and cost research issues in treatments for people with autistic disorders. *Journal of Autism and Developmental Disorders*, 30(6), 585-593.
- Jacobson, J.W., Mulick, J.A., & Green, G. (1998). Cost-benefit estimate for early intensive behavioral intervention for young children with autism – general model and single-state case. *Behavioral Interventions*, 13(4), 210-226.
- Janda, L.H. (1998). *Psychological testing: Theory and applications*. Toronto: Allyn and Bacon.
- Kasari, C. (2002). Assessing change in early intervention programs for children with autism. *Journal of Autism and Developmental Disorders*, 32, 447-461.

- Kline, P. (1986). *A handbook of test construction: Introduction to psychometric design*. New York: Methuen & Co.
- Knivsberg, A-M., Reichelt, K-L., Høien, T., & Nodland, M. (2003). Effect of a dietary intervention on autistic behavior. *Focus on Autism and Other Developmental Disabilities*, 18(4), 247-256.
- Lord, C., Risi, S., Lambrecht, L., Cook, Jr., E.H., Leventhal, B.L., DiLavore, P.C., Pickles, A., & Rutter, M. (2000). The autism diagnostic observation schedule – Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*, 30, 205-223.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24, 659-685.
- Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 97, 359-372.
- Menold, M.M. (2001). Association analysis of autistic disorder and SNP's in the chromosome 15. *American Journal of Human Genetics*, 69(4), 522.
- Metz, B., Mulick, J.A., & Butter, E.M. (2005). Autism: A late-20th-century fad magnet. In J.W., Jacobson, R.M., Foxx, & J.A., Mulick, (Eds.), *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice* (pp. 237-263). Mahwah, NJ: Lawrence Erlbaum Associates.
- Moes, F. (2002). Contextualized behavioral support in early intervention for children with autism and their families. *Journal of Autism and Developmental Disorders*, 32(6), 519-533.

- Mudford, O.C., Martin, N.T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: some characteristics of UK programs. *Research in Developmental Disorders*, 22(3), 173-182.
- Murphy, K.R., & Davishofer, C.O. (2001). *Psychological testing: Principles and applications* (5th Ed.). Upper Saddle River, NJ: Prentice-Hall, Inc.
- Nunnally, J.C., & Bernstein, I.H. (1994). *Psychometric theory* (3rd Ed.). Toronto: McGraw-Hill, Inc.
- Nurmi, E.L., Bradford, Y., Chen, Y., Hall, J., Arnone, B., Gardiner, M.B., et al. (2001). Linkage disequilibrium at the angelman syndrome gene ube3a in autism families. *Genomics*, 77, 105-113.
- Osterling, J.A. & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disorders*, 24(3), 247-257.
- Osterling, J.A., Dawson, G., & Munson, J.A. (2002). Early recognition of 1-year-old infants with autism spectrum disorder versus mental retardation. *Development and Psychopathology*, 14(2), 239-251.
- Ozonoff, S. (2006, June). *Studying autism in the first year of life: Constructs and cautions* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.
- Page, T. (2000). Metabolic approaches to the treatment of autism spectrum disorders. *Journal of Autism and Developmental Disabilities*, 30, 463-469.
- Pfeiffer, S.I., Norton, J., Nelson, L., & Shott, S. (1995). Efficacy of vitamin B6 and magnesium in the treatment of autism: A methodology review and summary of outcomes. *Journal of Autism and Developmental Disorders*, 25, 481-493.
- Ratliff-Schaub, K., Carey, T., Reeves, G.D., Rogers, M.A.M. (2005). Randomized control trial of transdermal secretin on behavior of children with autism. *Autism*, 9(3), 256-265.

- Robins, D.L., Fein, D., Barton, M.L., & Green, J.A. (2001). The modified checklist for autism in toddlers: An initial study investigating the early detection of autism and pervasive developmental disorder. *Journal of Autism and Developmental Disorders*, 31(2), 131-144.
- Scheuermann, B. & Webber, J. (2002). *Autism: Teaching does make a difference*. Belmont, CA: Wadsworth Group.
- Schopler, E., Reichler, R.J., & Renner, B.R. (2002). *The Childhood Autism Rating Scale*. Austin, TX: Pro-Ed, Inc.
- Shumway, S., Wetherby, A., Kahn, S., Plumb, A., & McCoy, D. (2006, June). *Communicative acts of children with autism spectrum disorders between 18 and 24 months of age* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.
- Smith, T., & Antolovich, M. (2000). Parental perceptions of supplemental interventions received by young children with autism in intensive behavior analytic treatment. *Behavioral Interventions*, 15, 83-97.
- Smith, T., Mruzek, D.W., & Mazingo, D. (2005). Sensory integrative therapy. In J.W., Jacobson, R.M., Foxx, & J.A., Mulick (Eds.), *Controversial Therapies for Developmental Disabilities: Fad, Fashion, and Science in Professional Practice*, (pp. 331-350). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Stone, W.L., & Henderson, L. (2006, June). *Challenges in screening young toddlers at high risk of autism* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.
- Watt, N., Wetherby, A., Barber, A., McCoy, D., & Book, L. (2006, June). *Repetitive and stereotyped behaviors in autism spectrum disorders from 18 to 24 months* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.

- Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief report: Recognition of autism spectrum disorder before 1-year of age: A retrospective study based on home videotapes. *Journal of Autism and Developmental Disorders*, 30, 157-162.
- Wetherby, A. (2006, June). *Identifying high-risk samples through population screening* (abstract). Paper presented at the International Meeting for Autism Research, Montreal.
- Wetherby, A.M., Woods, J., Allen, L., Cleary, J., Dickinson, H., & Lord, C. (2004). Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders*, 34 (5), 473-493.
- Whiteley, P., Rodgers, J., Savery, D., & Shattock, P. (1999). A gluten-free diet as an intervention for autism and associated spectrum disorders: Preliminary findings. *Autism*, 3(1), 45-65.
- Wolery, M. & Garfinkle, A.N. (2002). Measures in intervention research with young children who have autism. *Journal of Autism and Developmental Disorders*, 32, 463-478.
- Wolff, D.J., Clifton, K., Karr, C., & Charles, J. (2002). Pilot assessment of the subtelomeric regions of children with autism: Detection of a 2q deletion. *Genetic Medicine*, 4, 10-14.
- Wolff, S. (2004). The history of autism. *European Child and Adolescent Psychiatry*, 13(4), 201-208.
- Woods, J.J. & Wetherby, A.M. (2003). Early identification of and intervention for infants and toddlers who are a risk for autism spectrum disorders. *Language, Speech, and Hearing Services in Schools*, 34(3), 180-193.
- Zwaigenbaum, L., Bryson, S., Rogers, T., Roberts, W., Brian, J., & Szatmari, P. (2005). Behavioral manifestations of autism in the first year of life. *International Journal of Developmental Neuroscience*, 23, 143-152.

PARENT'S OBSERVATION CHECKLIST (POC)

PARENT INSTRUCTIONS:

- *This checklist is to be completed on your infant every month, if possible (minimum every 3 months, before 3 month phone or face-to-face interview)*
- *The following infant/toddler behaviors are grouped together by topic and are NOT developmentally sequenced.*
- *Over the past week, please indicate with a score from 1-4 whether the child has no difficulty (score 1) to severe problem (score 4) for each item. If you are unsure about how to score an item, you can test it out with your infant/toddler or ask your spouse or other caregivers, where possible.*
- *Depending upon the age of your child not all items will apply; mark N/A (not applicable).*

SCORING

- *A score of 1 indicates that you have no concern about the behavior and you feel that the infant is developing typically*
- *A score of 2 indicates a mild problem, i.e., child's behaviour is not completely typical of what you expect of his/her age*
- *A score of 3 indicates a moderate problem i.e., child behaviour is concerning, but not as severe as described in (4)*
- *A score of 4 indicates a severe problem that matches one or more of the descriptions provided*

	No evidence of difficulty 1	Mild problem 2	Moderate problem 3	Severe problem 4
1.	NAP TIME Sleeps well at nap time; wakes easily on his/her own Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Difficult to wake especially for feedings; or excessively light sleeper, need to tip-toe around during infant's nap time
2.	SLEEP DURATION AT NIGHT Sleeps at least four hours consecutively during the night; easy to get back to sleep Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Wakes frequently during the night; stays awake for long periods during the night
3.	SLEEP DURATION TOTAL PER DAY Sleeps at least 10 hours per day (night-time and naps combined) Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Sleeps less than 10 hours per day (night-time and naps combined)
4.	ACCEPTS BOTTLE/BREAST FEEDING Accepts breast or bottle-feeding readily Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Has difficulty sucking, or resists or appears to lose interest in feeding
5.	MILK/FORMULA TOLERANCE Tolerated breast milk or formula well; rarely spit up mild or formula Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Could not tolerate breast milk or formula; spit up frequently; needed milk substitute (e.g. soy)
6.	ACCEPTANCE OF NEW FOODS Accepts transition to <i>new</i> food readily, e.g., breast to bottle, pablum to puree, new tastes, new textures Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Strongly resists switch to bottle feeding or introduction of pablum/baby food; strongly resists/refuses new tastes and/or textures
7.	APPETITE Enjoys a variety of foods and eats an appropriate amount for child's age Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Eats and/or drinks small quantity and/or variety; or has a huge appetite, eats a lot more than expected for his/her age, always wanting food
8.	CUDDLING Accepts and enjoys cuddling and physical affection Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4		Actively resists being cuddled; dislikes being touched or picked up; or passive, indifferent to being picked up

9.	DEMANDS PARENT ATTENTION Cries or vocalizes and looks for parent when parent leaves room or parent is occupied	1-----1.5-----2-----2.5-----3-----3.5-----4	Appears indifferent to parent attention; prefers to be left alone most of the time
	Comments:		
10.	MOOD Easy to please; generally good mood; appears to be a happy child	1-----1.5-----2-----2.5-----3-----3.5-----4	Difficult to please; frequent colic symptoms; appears to be unhappy and/or irritable child
	Comments:		
11.	SMILING Readily smiles at people during social interactions	1-----1.5-----2-----2.5-----3-----3.5-----4	No social smile; might smile during play but not directed at people
	Comments:		
12.	LAUGHING Laughs readily in social situations; responds to other's laughter	1-----1.5-----2-----2.5-----3-----3.5-----4	Never laughs in social situations; may appear unaware of or indifferent to other's laughter; may laugh only when alone; other's can't figure out why
	Comments:		
13.	ATTACHMENT TO PARENTS Differentiates parents from other adults; may be shy with strangers; cries when left with less familiar adult	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not differentiate parents from other adults; would happily go to or stay with an adult; does not acknowledge parent's leaving the room
	Comments:		
14.	RECOGNITION OF PARENT'S VOICE Turns head toward mother or father's voice when held by another adult	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not appear to differentiate parent's voice from that of a stranger; no turning to look for parent when child hears parent's voice
	Comments:		
15.	PAIN REACTION Reacts to painful event (e.g., fall, cut) by crying or screaming; recovers quickly from mild bumps or discomfort	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not appear to feel pain in situations when others would find painful; or overreacts to what should be mild bumps or discomfort
	Comments:		
16.	SEEKS COMFORT WHEN HURT Seeks adult comfort when hurt; able to calm down when comforted	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not seek out adults when hurt; actively resists comforting when adult initiates; or difficult to calm when upset
	Comments:		

17.	APPROPRIATENESS OF EMOTIONS Crying or laughter is appropriate to the situation	1-----1.5-----2-----2.5-----3-----3.5-----4	Displays apparently unmotivated fits of crying or laughter; frequently can't figure out what he/she's crying or laughing about
	Comments:		
18.	ANTICIPATION TO BEING PICKED UP Shows excitement or anticipation when being picked up; raises arms to adult	1-----1.5-----2-----2.5-----3-----3.5-----4	Shows no awareness or anticipation of being picked up; does not raise arms to be picked up
	Comments:		
19.	CONSISTENCY OF RESPONSE Shows consistent response to familiar people, situations or places; easy to predict what will please or upset	1-----1.5-----2-----2.5-----3-----3.5-----4	Highly inconsistent response to familiar people, situations, or places; difficult to predict reaction; small changes can set off and upset
	Comments:		
20.	TOLERANCE OF TRANSITIONS Accepts transitions from one activity to another easily (e.g., play to meal or bath time)	1-----1.5-----2-----2.5-----3-----3.5-----4	Usually becomes very upset during transitions; may tantrum or cry for prolonged period
	Comments:		
21.	ATTENTION TO LOUD NOISE Turns head toward loud noise right away	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not respond to loud noises appears not to hear; or is overly reactive to loud noises and startles easily
	Comments:		
22.	RESPONSE TO NAME Responds to name by turning eyes and head toward person calling name; prefers human voice over object noise	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not respond to name when called; does not look at the caller; may appear deaf to the human voice
	Comments:		
23.	EYE CONTACT Makes eye contact easily during feeding, bathing ect.	1-----1.5-----2-----2.5-----3-----3.5-----4	Never makes eye contact; avoids eye contact all the time
	Comments:		
24.	INTEREST IN OBJECTS Shows interest in objects that move or make noises	1-----1.5-----2-----2.5-----3-----3.5-----4	Is excessively fearful of and tries to avoid certain object that move or make noises (e.g., fans, vacuums)
	Comments:		

25.	VISUAL TRACKING-SIDE TO SIDE Good visual tracking of an interesting object moved slowly side to side Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not track objects at all when object is slowly moved from side to side
26.	VISUAL TRACKING-UP AND DOWN Good visual tracking of an interesting object moved slowly up and down Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not track objects at all when object is moved slowly up and down
27.	INTEREST IN FACES Shows more interest in a person's face than in objects/toys Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Prefers looking at objects/toys' indifferent to faces or avoids faces
28.	SHIFTS ATTENTION TO PERSON Shifts attention from object/toy to person's face easily Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Has great difficulty shifting attention from an object/toy to a face
29.	SHIFTING ATTENTION BETWEEN EVENTS Shifts attention readily from one toy or event to another Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Gets "stuck" on one toy or activity and may not even notice when another toy or activity is introduced
30.	OBJECT PERMANENCE Searches for object/toy when hidden by adult or lost from view Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Immediately loses interest when object/toy is out of view, does not search for lost object/toy
31.	MUSCLE TONE Shows good muscle tone when sitting, rolling, crawling, or grasping objects Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Shows very poor muscle tone when sitting or moving; floppy baby; rarely initiates movement
32.	AGILITY IN MOVEMENT Developmentally appropriate movement: crawls, walks, runs, climbs smoothly Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Awkward in moving; may adopt unusual postures or gait (e.g., toe-walking); appears to move like a younger child

33.	EXPLORING NEW ENVIRONMENTS Enjoys exploring new environments and new toys	1-----1.5-----2-----2.5-----3-----3.5-----4	Shows no interest in new places or new toys; or actively tries to leave new place or discard new toy
	Comments:		
34.	APPROPRIATE TOY PLAY Plays appropriately with toys; explores, uses toy as intended	1-----1.5-----2-----2.5-----3-----3.5-----4	Plays inappropriately with toys; throws, destroys, plays with just one part not as intended; highly repetitive and stereotyped play
	Comments:		
35.	ATTENTION SPAN Plays with toys for amount of time appropriate to age (several minutes in infancy; gradually expanding with age to 15-30 min by age 2)	1-----1.5-----2-----2.5-----3-----3.5-----4	Attention is much briefer than expected given child's age; only able to focus for longer periods on TV, video, or limited set of objects of special interest
	Comments:		
36.	RANGE OF INTEREST IN TOYS Shows interest in variety of toys appropriate of child's age	1-----1.5-----2-----2.5-----3-----3.5-----4	Very limited range of interest in only one or two objects or toys not always appropriate to age
	Comments:		
37.	TOY VS. BODY PLAY Prefers to play appropriately with toys on own or with other	1-----1.5-----2-----2.5-----3-----3.5-----4	Prefers to play with his/her own body, using whole body movements (e.g., spinning, rocking) or small body movement (e.g., hand gazing, flapping)
	Comments:		
38.	BUILDING TOWERS Builds towers with at least 3 blocks without adult assistance	1-----1.5-----2-----2.5-----3-----3.5-----4	Can not build tower even with adult assistance; shows no interest and may resist tower building
	Comments:		
39.	IMITATES ACTIONS Readily imitates actions of others with toys or imitates body actions when asked "to this".	1-----1.5-----2-----2.5-----3-----3.5-----4	Never imitates action of others with toys or body actions of others when asked "to this".
	Comments:		
40.	IMITATES SOUNDS OR WORDS Readily imitates sounds or words of others, spontaneously or when asked "say ____"	1-----1.5-----2-----2.5-----3-----3.5-----4	Never imitates sounds or words of others, spontaneously or when asked "say ____"
	Comments:		

41.	<p>PRETEND PLAY Able to pretend play, as in making tea in toy cup, feeding doll with spoon, pushing toy car with appropriate sounds</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	No evidence of pretend play; may use toy cups or spoons as if real; may push car without sounds or pretend actions; no evidence that child is pretending
42.	<p>ACTIVITY LEVEL Shows appropriate activity level during unstructured play</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Appears lethargic or overly passive during unstructured play; or is overly excited and hyperactive during unstructured play
43.	<p>CRIES/VOCALIZES TO EXPRESS NEEDS Easily expresses needs with cries and vocalizations (hungry, wet, soiled or sleepy)</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not appear to be aware of own needs; does not cry when hungry or in discomfort
44.	<p>SOCIAL GAMES Enjoys playing social games (e.g., peek a boo, being swung, bounce on adult knee, songs, chase, ring-around- the-rosy)</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Indifferent to or avoids social games; resists by looking away, pushing away, or moving away when game initiated by others
45.	<p>POINTING TO REQUEST Uses index finger to point to ask for something; may use words along with point</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not point to make request; may use whole hand to reach toward the object of interest
46.	<p>POINTING TO SHARE INTEREST Uses index finger to point to indicate interest in something out of reach</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not point to interesting object to direct your attention; may look toward or reach toward
47.	<p>COORDINATES POINT AND GAZE When pointing to something child wants, checks that adult is looking in same direction</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	Point toward object he/she wants, but does not check to make sure adult is looking
48.	<p>POINTS IN RESPONSE TO QUESTIONS When asked "Where's the light (or other object out of reach)?" points with full hand reach or, later with index finger</p> <p>Comments:</p>	1-----1.5-----2-----2.5-----3-----3.5-----4	When asked a where question, does not look toward object; never attempts to point to or each toward the object requested

49.	FOLLOWS ADULT POINT WITH GAZE Looks toward an object when the adult points and says "look, there's ___!" Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not turn head in direction of adult point when adult points and says "Look there's a ___!"
50.	FOLLOWS SIMPLE DIRECTION When asked to do something simple, can respond appropriately when adult does not point (get your shoes, give me the dolly) Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Not able to understand or follow any adult direction unless adult uses gestures or physically prompts the child to follow through
51.	INTEREST IN BIRTHDAYS/PRESENTS Shows interest or excitement when he/she or sibling given birthday cake or present Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Appears indifferent when given a birthday cake or presented with a present
52.	BRINGING TOY TO REQUEST Brings toys/objects over to adult to request assistance or permission Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Never brings toys or objects to an adult to request assistance or permission
53.	BRINGING TOY TO SHARE ATTENTION Bring toys/objects over to adult to show or share joint attention Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Never brings toys to show adult or to share going attention
54.	WAITING Tolerates brief wait before needs can be met; remains calm but expectant while waiting Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Cannot tolerate any wait to have needs met; easily frustrated; quick to cry or tantrum if needs are not met immediately
55.	WAVES BYE-BYE Waves bye-bye when someone is leaving the home, without prompts to wave Comments:	1-----1.5-----2-----2.5-----3-----3.5-----4	Indifferent to visitors leaving; may resist prompts to wave bye-bye

56.	GREETINGS Acknowledges parents after brief period of absence with unprompted approach to smile, give or receive a hug, and/or says "hi"	1-----1.5-----2-----2.5-----3-----3.5-----4	Indifferent to parents when returning after period of absence; does not acknowledge with greeting, smile or hug; may resist parent's greeting.
	Comments:		
57.	INTEREST IN PEERS Shows interest in the play of other children or siblings; watches other children playing	1-----1.5-----2-----2.5-----3-----3.5-----4	Shows no interest in the activity of other children; ignores them as if they were not present
	Comments:		
58.	PLAY WITH PEERS Appropriate level of engagement with play side by side with same set of toys)	1-----1.5-----2-----2.5-----3-----3.5-----4	No interest in playing with or near siblings or peers; may do some chase or tickles with sibs, but won't share toys or materials; moves away from peers/sibs
	Comments:		
59.	COORDINATE GESTURES WITH COMMUNICATION Expresses needs easily by combining gestures and vocalizations or speech	1-----1.5-----2-----2.5-----3-----3.5-----4	Frequently frustrated in communicating needs; resorts to screaming, crying, tantrums, etc.; or does not persist, walks away when not understood the first time
	Comments:		
60.	COMMUNICATES WITH WORDS Consistently uses understandable words to communicate needs and interests	1-----1.5-----2-----2.5-----3-----3.5-----4	Does not have any words to express needs or interests; uses gestures and vocalizations only
	Comments:		
61.	CONVENTIONAL USE OF WORDS Uses conventional, common words or phrases to express needs and interest	1-----1.5-----2-----2.5-----3-----3.5-----4	Uses a lot of idiosyncratic, echolalic or made-up words and phrases to express needs and interests

INFANT BEHAVIORAL SUMMARIZED EVALUATION (IBSE)

The ISBE Scale is designed to provide a quantitative evaluation of the actual clinical state of autistic children. Each item is scored from 0 to 4 according to the frequency of appearance:

- 0 = Never
- 1 = Sometimes
- 2 = Often
- 3 = Very Often
- 4 = Continuously

1. Ignores people
2. Prefers aloneness
3. Poor social interaction
4. No social smile
5. No eye contact
6. Abnormal eye contact
7. Lack of vocal communication
8. Lack of appropriate facial expressions
9. Lack of appropriate gestures and/or expressive postures
10. No or poor imitation of gestures or voice of others
11. Too calm
12. Overly excited
13. Inappropriate use of objects
14. Stereotyped behavior
15. Hypoactivity
16. Hyperactivity
17. Hypotonia
18. Unusual postures
19. Auto-aggressiveness
20. Hetero-aggressiveness
21. Does not differentiate people
22. No expression of emotions
23. Unmotivated fits of crying and laughing
24. Intolerance to frustration
25. Resistance to change
26. Eating problems
27. Sleeping problems
28. Does not like to be touched
29. Interested only in body contact
30. Unstable attention, easily distracted
31. No reaction to auditory stimuli
32. Bizarre responses to auditory stimuli
33. Behavior variability

Adrien, J. L., Barthélémy, C., Perrot, A., Roux, S., Lenoir, P., Hameury, L., & Suavage, D. (1992). Validity and reliability of the Infant Behavioral Summarized Evaluation (IBSE): A rating scale for the assessment of young children with autism and developmental disorders. Journal of Autism and Developmental Disorders, 22, 375-394.

Ages and Stages Questionnaire

Ages & Stages Questionnaires: A Parent-Completed, Child-Monitoring System
Second Edition

By Diane Bricker and Jane Squires

with assistance from Linda Mounts, LaWanda Potter, Robert Nickel, Elizabeth Twombly, and Jane Farrell

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♦ **6 Month** ♦
Questionnaire

Please provide the following information.

Child's name: _____

Child's date of birth: _____

Child's corrected date of birth (if child is premature, add weeks of prematurity to child's date of birth):

Today's date: _____

Person filling out this questionnaire: _____

What is your relationship to the child? _____

Your telephone: _____

Your mailing address: _____

City: _____

State: _____ ZIP code: _____

List people assisting in questionnaire completion: _____

Administering program or provider: _____



YES SOMETIMES NOT YET

COMMUNICATION




Be sure to try each activity with your child.

- | | | | | |
|---|--------------------------|--------------------------|--------------------------|-----|
| 1. Does your baby make high-pitched squeals? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 2. When playing with sounds, does your baby make grunting, growling, or other deep-toned sounds? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 3. If you call your baby when you are out of sight, does she look in the direction of your voice? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 4. When a loud noise occurs, does your baby turn to see where the sound came from? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 5. Does your baby make sounds like "da," "ga," "ka," and "ba"? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 6. If you copy the sounds your baby makes, does your baby repeat the sounds back to you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |

COMMUNICATION TOTAL ___

GROSS MOTOR

Be sure to try each activity with your child.

- | | | | | |
|--|---|--------------------------|--------------------------|-----|
| 1. While on his back, does your baby lift his legs high enough to see his feet? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 2. When she is on her tummy, does your baby straighten both arms and push her whole chest off the bed or floor? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 3. Does your baby roll from his back to his tummy, getting both arms out from under him? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| 4. When you put her on the floor, does your baby lean on her hands while sitting? (If she already sits up straight without leaning on her hands, check "yes" for this item.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| |  | | | |
| 5. If you hold both hands just to balance him, does your baby support his own weight while standing? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| |  | | | |
| 6. Does your baby get into a crawling position by getting up on her hands and knees? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
| |  | | | |

GROSS MOTOR TOTAL ___

FINE MOTOR

Be sure to try each activity with your child.

- | | | | | |
|---|--------------------------|--------------------------|--------------------------|-----|
| 1. Does your baby grab a toy you offer and look at it, wave it about, or chew on it for about 1 minute? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | ___ |
|---|--------------------------|--------------------------|--------------------------|-----|

YES SOMETIMES NOT YET

FINE MOTOR *(continued)*

2. Does your baby reach for or grasp a toy using both hands at once?

☐ ☐ ☐ ☐

3. Does your baby reach for a crumb or Cheerio and touch it with his finger? (If he already picks up a small object the size of a pea, check "yes" for this item.)


☐ ☐ ☐ ☐

4. Does your baby pick up a small toy, holding it in the center of her hands with her fingers around it?


☐ ☐ ☐ ☐

5. Does your baby try to pick up a crumb or Cheerio by using his thumb and all his fingers in a raking motion, even if he isn't able to pick it up? (If he already picks up the crumb or Cheerio, check "yes" for this item.)


☐ ☐ ☐ ☐

6. Does your baby usually pick up a small toy with only one hand?


☐ ☐ ☐ ☐
FINE MOTOR TOTAL ☐**PROBLEM SOLVING** *Be sure to try each activity with your child.*

1. When a toy is in front of her, does your baby reach for it with both hands?

☐ ☐ ☐ ☐

2. When he is on his back, does your baby turn his head to look for a toy when he drops it? (If he already picks it up, check "yes" for this item.)

☐ ☐ ☐ ☐

3. When she is on her back, does your baby try to get a toy she has dropped if she can see it?

☐ ☐ ☐ ☐

4. Does your baby often pick up toys and put them in his mouth?


☐ ☐ ☐ ☐

5. Does your baby pass a toy back and forth from one hand to the other?


☐ ☐ ☐ ☐

6. Does your baby play by banging a toy up and down on the floor or table?


☐ ☐ ☐ ☐
PROBLEM SOLVING TOTAL ☐

YES SOMETIMES NOT YET

PERSONAL-SOCIAL*Be sure to try each activity with your child.*

1. When in front of a large mirror, does your baby smile or coo at herself?


☐ ☐ ☐ _____

2. Does your baby act differently toward strangers than he does with you and other familiar people? (Reactions to strangers may include staring, frowning, withdrawing, or crying.)

☐ ☐ ☐ _____

3. While lying on her back, does your baby play by grabbing her foot?


☐ ☐ ☐ _____

4. When in front of a large mirror, does your baby reach out to pat the mirror?


☐ ☐ ☐ _____

5. While on his back, does your baby put his foot in his mouth?


☐ ☐ ☐ _____

6. Does your baby try to get a toy that is out of reach? (She may roll, pivot on her tummy, or crawl to get it.)

☐ ☐ ☐ _____

PERSONAL-SOCIAL TOTAL _____

OVERALL*Parents and providers may use the back of this sheet for additional comments.*

1. Do you think your child hears well?

YES ☐ NO ☐

If no, explain: _____

2. Does your baby use both hands equally well?

YES ☐ NO ☐

If no, explain: _____

3. When you help your baby stand, are his feet flat on the surface most of the time?

YES ☐ NO ☐

If no, explain: _____

4. Does either parent have a family history of childhood deafness or hearing impairment?

YES ☐ NO ☐

If yes, explain: _____

5. Do you have concerns about your child's vision?

YES ☐ NO ☐

If yes, explain: _____

6. Has your child had any medical problems in the last several months?

YES ☐ NO ☐

If yes, explain: _____

7. Does anything about your child worry you?

YES ☐ NO ☐

If yes, explain: _____

6 Month ASQ Information Summary

Child's name: _____

Date of birth: _____

Person filling out the ASQ: _____

Corrected date of birth: _____

Mailing address: _____

Relationship to child: _____

Telephone: _____

City: _____ State: _____ ZIP: _____

Today's date: _____

Assisting in ASQ completion: _____

OVERALL: Please transfer the answers in the Overall section of the questionnaire by circling "yes" or "no" and reporting any comments.

- | | | | |
|--|--------|---|--------|
| 1. Hears well?
Comments: | YES NO | 4. Family history of hearing impairment?
Comments: | YES NO |
| 2. Uses both hands equally well?
Comments: | YES NO | 5. Vision okay?
Comments: | YES NO |
| 3. Baby's feet flat on the surface?
Comments: | YES NO | 6. Recent medical problems?
Comments: | YES NO |
| | | 7. Other concerns?
Comments: | YES NO |

SCORING THE QUESTIONNAIRE

- Be sure each item has been answered. If an item cannot be answered, refer to the ratio scoring procedure in *The ASQ User's Guide*.
- Score each item on the questionnaire by writing the appropriate number on the line by each item answer.
YES = 10 SOMETIMES = 5 NOT YET = 0
- Add up the item scores for each area, and record these totals in the space provided for area totals.
- Indicate the child's total score for each area by filling in the appropriate circle on the chart below. For example, if the total score for the Communication area was 50, fill in the circle below 50 in the first row.

Total	0	5	10	15	20	25	30	35	40	45	50	55	60
Communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gross motor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fine motor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problem solving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal-social	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Total	0	5	10	15	20	25	30	35	40	45	50	55	60

Examine the blackened circles for each area in the chart above.

- If the child's total score falls within the ☐ area, the child appears to be doing well in this area at this time.
- If the child's total score falls within the ☒ area, talk with a professional. The child may need further evaluation.

OPTIONAL: The specific answers to each item on the questionnaire can be recorded below on the summary chart.

Score Cutoff		Communication	Gross motor	Fine motor	Problem solving	Personal-social
6 months	Communication	1 <input type="radio"/> <input type="radio"/> <input type="radio"/>	1 <input type="radio"/> <input type="radio"/> <input type="radio"/>	1 <input type="radio"/> <input type="radio"/> <input type="radio"/>	1 <input type="radio"/> <input type="radio"/> <input type="radio"/>	1 <input type="radio"/> <input type="radio"/> <input type="radio"/>
	Gross motor	2 <input type="radio"/> <input type="radio"/> <input type="radio"/>	2 <input type="radio"/> <input type="radio"/> <input type="radio"/>	2 <input type="radio"/> <input type="radio"/> <input type="radio"/>	2 <input type="radio"/> <input type="radio"/> <input type="radio"/>	2 <input type="radio"/> <input type="radio"/> <input type="radio"/>
	Fine motor	3 <input type="radio"/> <input type="radio"/> <input type="radio"/>	3 <input type="radio"/> <input type="radio"/> <input type="radio"/>	3 <input type="radio"/> <input type="radio"/> <input type="radio"/>	3 <input type="radio"/> <input type="radio"/> <input type="radio"/>	3 <input type="radio"/> <input type="radio"/> <input type="radio"/>
	Problem solving	4 <input type="radio"/> <input type="radio"/> <input type="radio"/>	4 <input type="radio"/> <input type="radio"/> <input type="radio"/>	4 <input type="radio"/> <input type="radio"/> <input type="radio"/>	4 <input type="radio"/> <input type="radio"/> <input type="radio"/>	4 <input type="radio"/> <input type="radio"/> <input type="radio"/>
	Personal-social	5 <input type="radio"/> <input type="radio"/> <input type="radio"/>	5 <input type="radio"/> <input type="radio"/> <input type="radio"/>	5 <input type="radio"/> <input type="radio"/> <input type="radio"/>	5 <input type="radio"/> <input type="radio"/> <input type="radio"/>	5 <input type="radio"/> <input type="radio"/> <input type="radio"/>

Administering program or provider: _____

FAMILY INFORMATION QUESTIONNAIRE

1. Date (month-day-year): _____
2. Relationship of informant to the child/children in the study: _____
3. Participant Child's Initials (first, middle, last name): 1) _____ 2) _____
4. Participant Child's Date of Birth (month-day-year): 1) _____ 2) _____

PARENT/FAMILY INFORMATION

5. Number of all children and adolescents (up to age 18 yrs) living in the home: _____
 Age: _____ Date of birth (m/d/y): _____
 Age: _____ Date of birth (m/d/y): _____
 Age: _____ Date of birth (m/d/y): _____
 Age: _____ Date of birth (m/d/y): _____
 Age: _____ Date of birth (m/d/y): _____
6. Number of all adults (19 yrs and over) living in the home: _____
7. Location of home (nearest city or town): _____
8. Type of dwelling (Circle ONE):
Apartment Townhouse Boarding home Semi-detached Detached Shelter
9. Do you (Circle ONE)
Own Rent Neither (specify): _____

10. Present marital status of parents (Circle ONE)

Married Living together Separated Divorced Widowed

11. Total family income before taxes (Circle ONE)

less than \$5,000 \$5,000-9,999 \$10,000-14,999 \$15,000-19,999 \$20,000-24,999

\$25,000-29,999 \$30,000-34,999 \$35,000-39,999 \$40,000-44,999 \$45,000-49,999

\$50,000-54,999 \$55,000-59,999 \$60,000-64,999 \$65,000-69,999 \$70,000-74,999

\$75,000-79,999 \$80,000-84,999 \$85,000-89,999 \$90,000-94,999 more than \$95,000

INFORMATION ABOUT MOTHER

12. Mother's date-of-birth (month-day-year): _____

13. How many years did mother spend in high school (secondary school): _____

14. How many years did mother spend in post-secondary school (college/university): _____

15. Diploma/degree obtained by mother (Circle all that apply):

None Trade Diploma College University Graduate/Professional

16. Mother had special education experience when in school. (Circle ONE)

No Yes (specify): _____

17. Current occupation of mother: _____

18. Mother works (Circle ONE)

Full-time Part-time No

19. In general, how is mother's health? (Circle ONE)

Excellent Very good Good Fair Poor Don't know

20. Have any of mother's relatives been diagnosed with Autism?

No Yes (specify relationship): _____

INFORMATION ABOUT FATHER

21. Father's date-of-birth (month-day-year): _____

22. How many years did father spend in high school (secondary school): _____

23. How many years did father spend in post-secondary school (college/university): _____

24. Diploma/degree obtained by father (Circle all that apply):

None Trade Diploma College University Graduate/Professional

25. Father had special education experience when in school. (Circle ONE)

No Yes (specify): _____

26. Current occupation of father: _____

27. Father works (Circle ONE)

Full-time Part-time No

28. In general, how is father's health? (Circle ONE)

Excellent Very good Good Fair Poor Don't know

29. Have any of father's relatives been diagnosed with Autism?

No Yes (specify relationship): _____

CURRENT SERVICES

30. List all services the family is currently receiving such as preschool, social, health, respite, and support services. Describe the type of services offered and the reasons for them. It is not necessary to list them by name:

CHILD 1 INFORMATION

31. Child's date of birth (m/d/y) _____; Child's initials _____

32. Child sex (Circle ONE) *Male Female*

33. Child's relationship to the family (Circle ONE)

natural child foster child adopted child other (specify): _____

34. Child's birth order (Specify number): _____

35. Child's siblings (Specify numbers of each category; put 0 if none)

younger brothers: _____
younger sisters: _____

older brothers: _____
older sisters: _____

36. Is the child a twin? (Circle ONE)

No Yes, fraternal Yes, identical Triplet Quadruplet

37. In general, how is your child's health?

Excellent Very good Good Fair Poor Don't know

38. Child age when a developmental problem was first noticed (if none, write *none*): _____

39. Child age when a behavioural problem was first noticed (if none, write *none*): _____

40. Child age at first formal diagnosis of disability (if none, write *none*): _____ months

41. Child's diagnosis (as told to you by a professional; ✓ all that apply):

- | | |
|---|---|
| <input type="checkbox"/> Autistic disorder | |
| <input type="checkbox"/> Rett's disorder | |
| <input type="checkbox"/> Childhood Disintegrative disorder | |
| <input type="checkbox"/> Asperger's disorder | |
| <input type="checkbox"/> Pervasive Developmental Disorder – Not Otherwise Specified | |
| <input type="checkbox"/> Down syndrome | |
| <input type="checkbox"/> Learning disorder | <input type="checkbox"/> Fragile X |
| <input type="checkbox"/> Communication disorder | <input type="checkbox"/> Prader-Willi syndrome |
| <input type="checkbox"/> Cerebral Palsy | <input type="checkbox"/> Lesch-Nyan syndrome |
| <input type="checkbox"/> Spina Bifida | <input type="checkbox"/> Williams syndrome |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Fetal Alcohol syndrome |
| <input type="checkbox"/> Brain damage | |
| <input type="checkbox"/> other organic/genetic condition (please specify): _____ | |
| <input type="checkbox"/> other condition (please specify): _____ | |
| <input type="checkbox"/> child has no formal diagnosis at this time | |

42. Child's current level of developmental delay as told to you by a professional (circle ONE):

<i>No delay</i>	<i>Borderline</i>	<i>Mild</i>	<i>Moderate</i>
<i>Severe</i>	<i>Profound</i>	<i>No information available at this time</i>	

43. Child's current level of developmental delay in your own opinion (circle ONE):

<i>No delay</i>	<i>Borderline</i>	<i>Mild</i>	<i>Moderate</i>
<i>Severe</i>	<i>Profound</i>	<i>Unknown</i>	

44. Child's other problems (✓ all that apply):

- ☐ hearing problem (please specify): _____
- ☐ vision problem (please specify): _____
- ☐ movement problem (please specify): _____
- ☐ seizures (please specify how many grand mals per month): _____
- ☐ chronic ear infections (Are tubes inserted into ears?) *Yes* *No*
- ☐ headaches
- ☐ eating disorder (please specify): _____
- ☐ chronic constipation
- ☐ chronic diarrhea

- ☐ asthma
☐ allergies (please specify): _____
☐ recurrent skin rash
☐ problem with a major organ (please specify): _____
☐ frequent colds and flus
☐ attention deficit
☐ hyperactivity
☐ other medical/health problems (please specify): _____

45. Medications (Please list all medications child is currently taking and their purpose):

PRENATAL AND BIRTH HISTORY OF CHILD 1

46. Length of pregnancy: full-term: _____ premature? (how many weeks): _____

47. Duration of Labour : _____ hours

48. Any medical complications during **pregnancy**? (Circle ONE)

No *Yes (Please specify)* _____

49. Any medical complications during **birth**? (Circle ONE)

No *Yes (Please specify)* _____

50. Length of hospitalization: _____ days

51. Birth Weight: _____

CHILD 2 INFORMATION

(only complete this section if you have another child also in the study)

52. Child's date of birth (m/d/y) _____; Child's initials _____

53. Child sex (Circle ONE) *Male* *Female*

54. Child' relationship to the family (Circle ONE)

natural child *foster child* *adopted child* *other (specify):* _____

55. Child's birth order (Specify number): _____

56. Child's siblings (Specify numbers of each category; put 0 if none)

younger brothers: _____
 younger sisters: _____

older brothers: _____
 older sisters: _____

57. Is the child a twin? (Circle ONE)

No Yes, fraternal Yes, identical Triplet Quadruplet

58. In general, how is your child's health?

Excellent Very good Good Fair Poor Don't know

59. Child age when a developmental problem was first noticed (if none, write *none*): _____

60. Child age when a behavioural problem was first noticed (if none, write *none*): _____

61. Child age at first formal diagnosis of disability (if none, write *none*): _____ months

62. Child's diagnosis (as told to you by a professional; ✓ all that apply):

- | | |
|---|---|
| <input type="checkbox"/> Autistic disorder | |
| <input type="checkbox"/> Rett's disorder | |
| <input type="checkbox"/> Childhood Disintegrative disorder | |
| <input type="checkbox"/> Asperger's disorder | |
| <input type="checkbox"/> Pervasive Developmental Disorder – Not Otherwise Specified | |
| <input type="checkbox"/> Down syndrome | |
| <input type="checkbox"/> Learning disorder | <input type="checkbox"/> Fragile X |
| <input type="checkbox"/> Communication disorder | <input type="checkbox"/> Prader-Willi syndrome |
| <input type="checkbox"/> Cerebral Palsy | <input type="checkbox"/> Lesch-Nyan syndrome |
| <input type="checkbox"/> Spina Bifida | <input type="checkbox"/> Williams syndrome |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Fetal Alcohol syndrome |
| <input type="checkbox"/> Brain damage | |
| <input type="checkbox"/> other organic/genetic condition (please specify): _____ | |
| <input type="checkbox"/> other condition (please specify): _____ | |
| <input type="checkbox"/> child has no formal diagnosis at this time | |

63. Child's current level of developmental delay as told to you by a professional (circle ONE):

No delay	Borderline	Mild	Moderate
Severe	Profound	No information available at this time	

64. Child's current level of developmental delay in your own opinion (circle ONE):

No delay	Borderline	Mild	Moderate
----------	------------	------	----------

*Severe**Profound**Unknown*

65. Child's other problems (✓ all that apply):

- ☐ hearing problem (please specify): _____
☐ vision problem (please specify): _____
☐ movement problem (please specify): _____
☐ seizures (please specify how many grand mals per month): _____
☐ chronic ear infections (Are tubes inserted into ears?) *Yes No*
☐ headaches
☐ eating disorder (please specify): _____
☐ chronic constipation
☐ chronic diarrhea
☐ asthma
☐ allergies (please specify): _____
☐ recurrent skin rash
☐ problem with a major organ (please specify): _____
☐ frequent colds and flus
☐ attention deficit
☐ hyperactivity
☐ other medical/health problems (please specify): _____

66. Medications (Please list all medications child is currently taking and their purpose):

PRENATAL AND BIRTH HISTORY OF CHILD 2

67. Length of pregnancy: full-term: _____ premature? (how many weeks): _____

68. Duration of Labour : _____ hours

69. Any medical complications during **pregnancy**? (Circle ONE)*No Yes (Please specify)* _____70. Any medical complications during **birth**? (Circle ONE)*No Yes (Please specify)* _____

71. Length of hospitalization: _____ days

72. Birth Weight: _____

SERVICE QUESTIONNAIRE – complete one for each child

Name of Child: _____ Child DOB (M-D-Y): _____ Date: _____

Child Code No. _____ Name of Informant: _____ Relationship to Child: _____

Service (see listing of specific services included under each category)	Start m-y	End m-y	Contact time & where	Parent Involvement	Structure	Need/Importance/ Want It	Satisfaction	Effectiveness
<i>Sensory Integration</i>				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 very not satisfied at all	1 2 3 4 5 6 7 very effective
Comments								
<i>Secretin</i>				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 very satisfied at all	1 2 3 4 5 6 7 very effective
Comments								
<i>Diet Therapy</i>				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 very satisfied at all	1 2 3 4 5 6 7 very effective

Service (see listing of specific services included under each category)	Start m-y	End m-y	Contact time & where	Parent Involvement	Structure	Need/Importance/ Want It	Satisfaction	Effectiveness
Comments								
Prescription Medication				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very satisfied at all	1 2 3 4 5 6 7 not very at all effective
Comments								
Vitamin Therapy				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very satisfied at all	1 2 3 4 5 6 7 not very at all effective
Comments								

Service (see listing of specific services included under each category)	Start m-y	End m-y	Contact time & where	Parent Involvement	Structure	Need/Importance/ Want It	Satisfaction	Effectiveness
<i>Herbal Remedies</i>				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very not at all satisfied	1 2 3 4 5 6 7 very not at all effective
Comments:								
Behavioural Interventions				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very not at all satisfied	1 2 3 4 5 6 7 very not at all effective
Comments:								
Specialized Preschool				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very not at all satisfied	1 2 3 4 5 6 7 very not at all effective
Comments:								
Special Needs Worker				1 2 3 4 5 6 7 none very at all involved	1 2 3 4 5 6 7 none very at all structured	1 2 3 4 5 6 7 very much not at all	1 2 3 4 5 6 7 very not at all satisfied	1 2 3 4 5 6 7 very not at all effective

Service (see listing of specific services included under each category)	Start m-y	End m-y	Contact time & where	Parent Involvement	Structure	Need/Importance/ Want It	Satisfaction	Effectiveness
Comments:								
Regular Daycare				1 2 3 4 5 6 7 none at all very involved at all	1 2 3 4 5 6 7 very none structured at all	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 not at all very satisfied	1 2 3 4 5 6 7 very effective
Comments:								
Our provided service – advice from interviewer Describe:				1 2 3 4 5 6 7 none at all very involved at all	1 2 3 4 5 6 7 very none structured at all	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 not at all very satisfied	1 2 3 4 5 6 7 very effective
Comments								
Other service or child and family Describe:				1 2 3 4 5 6 7 none at all very involved at all	1 2 3 4 5 6 7 very none structured at all	1 2 3 4 5 6 7 very not much at all	1 2 3 4 5 6 7 not at all very satisfied	1 2 3 4 5 6 7 very effective

Service (see listing of specific services included under each category)	Start m-y	End m-y	Contact time & where	Parent Involvement	Structure	Need/Importance/ Want It	Satisfaction	Effectiveness
Comments								

Follow-Up Questions

1. Are there any other services that you would like to receive, yet you have not? If yes, why have you not yet received it?

2. How did you find out about each therapy that you have implemented?

3. Why did you choose these particular therapies as opposed to different ones?

4. If you are involved in providing therapy to your child, who/how were you trained?

5. Have there been any side effects (positive or negative) to any of the therapies that you have provided to your child?

6. How have these interventions affected your stress levels related to parenting and the problems that your younger child may have

(on a 7-point scale)?

1	2	3	4	5	6	7
---	---	---	---	---	---	---

greatly increased my my levels as a parent	my stress levels as a parent	no change in my stress levels as a parent	greatly decreased stress
---	------------------------------	--	-----------------------------

Comments:

7. How have these interventions affected your feelings of competence as a parent (on a 7-point scale)?

1	2	3	4	5	6	7
greatly decreased my feelings of competence as a parent			no change in my feelings of competence as a parent			greatly increased my feelings of competence as a parent

Comments:

Letter of Invitation

October 2005

Title of Study: An Evaluation of Interventions for Infants at Biological Risk for Autism Spectrum Disorders

Principal Investigator: Kaleigh Regehr, Masters Student, Department of Child and Youth Studies, Brock University

Faculty Supervisor: Maurice Feldman, professor, Department of Child and Youth Studies, Brock University

I, Kaleigh Regehr, Master's Student, from the Department of Child and Youth Studies, Brock University, invite you to participate in a research project entitled "An Evaluation of Interventions for Infants At-Risk for Autism Spectrum Disorders". You are being invited specifically because you have an older child who has been diagnosed with autism and have a younger infant who is thus genetically at-risk for autism.

The purpose of this research project is twofold. One is to establish a new test that will be able to detect autistic symptoms in infancy so that intervention can start as early as possible. The other purpose of this research is to begin to list the interventions that parents are currently using when they detect autistic symptoms in their young infants as well as the interventions that are being used with their older autistic child.

The expected duration of this study is 3 months, from October to December 2005.

This research should benefit families who have children who are at-risk for autism. By participating in this research, you may feel good about the opportunity to discuss ways of improving the service system in a study that eventually may influence policy makers, service funders and service providers.

This study is not being sponsored by any company, yet is being run as part of a multi-centered study at Queen's and Brock University. Queen's University is conducting interviews that you are aware of and taking part in, and this research will build upon that being done at Queen's.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you

Kaleigh Regehr

Kaleigh Regehr
Masters Student

Phone:

Email: kr04ft@brocku.ca

Maurice Feldman
Professor

Phone: 905-688-5550 ext. 3785

Email: maurice.feldman@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file #05-012 REGEHR)

INFORMED CONSENT LETTER

October 2005

Title of Study: Evaluations of Interventions for Infants at Biological Risk for Autism Spectrum Disorders

Principal Investigator: Kaleigh Regehr, Masters Student, Department of Child and Youth Studies, Brock University

Faculty Supervisor: Dr. Maurice Feldman, Professor, Department of Child and Youth Studies, Brock University

Name of Participant (please print): _____

- I understand that this study involves research, and that I am being invited to participate
- I understand that there are two purposes of this study.
- I understand that the first purpose is to determine if the questionnaires I am currently completing as part of my involvement in the study, "The Infants at Risk for Autism (TIARA) Program: Identification of and Intervention for, Very Early Signs of Autism Spectrum Disorders (ASD)" can indeed identify early signs of autism in infants that are at a higher risk of developing autism because their older sibling(s) already has it.
- I understand that the second purpose is to list the interventions that parents are currently using when they detect problems in their at-risk infants as well as the interventions that are being used with their older children already diagnosed with ASD.
- I understand that I will be asked to complete two new questionnaires, The Family Information Questionnaire and the Service Questionnaire, in a phone interview that should last about one hour. These two questionnaires are enclosed with this consent form for me to look at.
- I understand that the Family Information Questionnaire asks descriptive questions about my family (e.g., number of children, parent education and occupation). I am asked this information so that the researchers can have a better understanding of the characteristics of the families who participated and see if there is any relationship between family characteristics and services used.
- I understand that the Service Questionnaire asks me about the services I am receiving or want for both the infant and my older child with ASD. The Service Questionnaire asks me several questions such as rating on a 1 to 7 scale how much I am involved in the service, how much I feel that I need that service, how effective I think the service is and how satisfied I am with the service. There also are questions related to my choice of services, parental stress and competence.
- I understand that there is no obligation to answer any questions that I feel is invasive, offensive or inappropriate.
- I understand that there are no known risks associated with my participation in this study. I may benefit from feeling good that I have the opportunity to participate in research that may eventually help other families and improve the service system.
- I understand that my family's identity will be protected and that my name (or any family member) will never be used in presentations and publications.
- I understand that only the Principal Investigator and her Faculty Supervisor will have access to my data, and that all information will be stored securely in a locked filing cabinet in a locked office until July 2012 when all information and data will be destroyed by machine shredding of papers and electronic deletion of computer hard drive, remote drive and disk files.

- I understand that participation is voluntary; refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled and I may discontinue participation at any time without penalty or loss of benefits, to which I am otherwise entitled.
- I understand that I will be contacted by the Principal Investigator to arrange a date and time for the interview, and once to complete the interview.
- I understand that after completion of the study, the results will be analyzed, and I will be sent a debriefing form that will describe the results of the study. If the research does get published, a letter will be sent to me letting me know where and when I can find it.
- I understand that under extraordinary circumstances, confidentiality cannot be ensured because of mandatory reporting laws (e.g. suspected child abuse, reportable communicable diseases).
- I understand that I may be contacted to participate in similar studies. I understand that my consent here does not mean I agree to be in those studies, but just to be contacted to learn about them.
- I understand that if I have any pertinent questions about my rights as a research participant, I can contact the Brock University Research Ethics Officer (905 688-5550 ext. 3035, reb@brocku.ca)

I _____,

1. *Have read and understood the relevant information regarding this research project*
2. *Understand that I may ask questions at any time*
3. *Indicate free consent to research participation by signing this research consent form*

Participant's Signature: _____

I have explained this study to the participant

Researcher's Signature: _____

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This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 05-012 REGEHR)



