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Prognostic Factors in Children with Autism:

An Exploration

by

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ABSTRACT

The present study explored the variables related to prognosis in children with autism. More specifically, the following factors were examined: 1) family variables, 2) behavioral disturbance, 3) severity, 4) age at time of diagnosis, 5) health conditions and disorders, 6) gender, and 7) the acquisition of developmental milestones. Thirty-nine children (M age in months = 46.23, SD 8.53) who had been diagnosed with autism or PDD and assessed on more than one occasion, took part in this study. Prognosis was measured by mean monthly ratios of change in the areas of cognitive functioning, adaptive functioning, communication, autistic symptomatology, and overall functioning. Results indicated that divorce, the ability to address a familiar other, presence of behavioral rigidity, mental retardation, gender, and age of first word, were related to prognosis. Results and limitations of the study are discussed. Directions for further research are outlined.

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Chapter One

Introduction and Literature Review

Autism is widely regarded as the most severe disorder of childhood and adolescence (Volkmar, 1997). It is diagnosed on the basis of three core features: abnormal communicative development, abnormal social development, and the presence of restricted interests and repetitive activities (Baron-Cohen & Hammer, 1997). Gender differences exist in autism, as approximately three to five times more males than females are diagnosed with the disorder (Klinger & Dawson, 1996). There is also evidence to demonstrate that females with autism may be more severely affected than males (Cicchetti & Cohen, 1995). Although the cognitive ability of individuals with autism varies greatly, the majority of the population (i.e. 70-80 %) functions within the mentally retarded range (Bryson et al., 1988). In spite of the fact that autism has existed as a separate diagnostic category for several years, the complexity of this pervasive developmental disorder continues to bewilder researchers. For instance, autism is regarded as etiologically heterogeneous (Piven et al., 1993). With causation research continuing to produce varying results, researchers are left without resolve.

Current follow-up studies suggest that the outcome for children with autism is variable, (Stone, Maclean, & Hogan, 1995), as many factors appear to play a role in the course of the disorder (Lord & Paul, 1997). According to Lotter (1974; 1978), the presence of functional language by age five is one of the most potent predictors of outcome in individuals with autism. Other variables such as measured intelligence (i.e. IQ) (Volkmar, 1996) and the development of social skills (Popper & Steingard, 1996) are also reported to be relevant to prognosis. However, much remains unknown about other variables which impact outcome.

To this end, the present study attempted to explore prognostic factors in children with autism. These factors were broadly grouped into the following categories: family variables (e.g. family composition), the presence of behavioral disturbances, the severity of autism at time of diagnosis, the child's age at time of diagnosis, the presence of health-related conditions and disorders, the child's gender, and the time at which specific developmental milestones were achieved. The primary purpose of this study was to ascertain which variables were related to prognosis in children with autism. Prognosis was measured by gains in cognitive ability, social skills, language abilities, and by reductions in autistic symptomatology. Gains in overall functioning (i.e. these four areas combined) were also examined. Prior to discussing the current study in more details general information regarding the syndrome of autism will be presented. To be more specific, the history of the syndrome will be reviewed. This will be followed by a discussion of established diagnostic criteria, associated disorders, population characteristics, epidemiology, gender differences, etiology, course, and accepted intervention strategies.

General Information

Historical Context

The term "autism" was first coined by Bleuler (1911) to describe persons diagnosed with schizophrenia who demonstrated a loss of contact with reality. Kanner (1943) went on to use the term "infantile autism" to describe children, who in contrast to normally developing infants, displayed a remarkable lack of interest in others. Autism, originating from the Greek word "autos", meaning "self", represented Kanner's observation of children who appeared to be isolated from others and from things outside of themselves. According to Kanner (1943), the fundamental aspect of infantile autism was the "inability to relate in the ordinary way to people and situations from the beginning of life" (p. 242). Instead, these children demonstrated more

interest in the nonsocial environment than the social realm (Volkmar, Klin, Marans, & Cohen, 1997).

In 1958, Kanner presented a strong argument regarding the specificity of infantile autism and the unique cluster of symptoms. In addition, he maintained that infantile autism was a disease “sui generis” (i.e., of genetic basis) and he received considerable support of his views from other researchers in the field (Prior, Perry, & Gajzago, 1975). Other characteristics of infantile autism discussed by Kanner (1943) included: the presence of stereotyped and self-stimulatory movements, occasional areas of isolated proficiency or interest, a marked resistance to change, and unusual and often limited development of language.

Diagnostic Criteria

Autism or Autistic Disorder (as stated in The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition; APA, 1994) is a Pervasive Developmental Disorder (PDD). Pervasive developmental disorders (PPDs) are a group of disorders which are characterized by deviance and specific delays in communication, social, and cognitive development, that develop during the first years of a child’s life (Volkmar et al., 1997). Over time, the definitions and descriptions of autism have been modified and refined in the light of new research findings (Marcus & Stone, 1993). Clinicians and researchers have now attained consensus on the validity of autism as a diagnostic category, as well as on the various features central to its definition (Rutter, 1996). This consensus has made possible the development of the two major diagnostic systems, The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychological Association, 1994) (See Appendix A) and the World Health Organization (WHO) International Classification of Diseases (WHO, 1993). According to

Volkmar et al. (1997), the diagnostic criteria outlined in DSM-IV (American Psychological Association, 1994) are historically continuous with previous definitions of autism.

Presently, several diagnostic instruments are used by professionals in conjunction with the aforementioned diagnostic systems (Pilowsky et al., 1998). Psychometric measures such as The Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1988), The Autism Diagnostic Interview-Revised (Le Couteur et al., 1989; Wing & Gould, 1978) and The Autism Behavior Checklist (Krug, Arick, & Almond, 1980) may be employed when addressing the issue of diagnosis.

Pervasive Developmental Disorders are also referred to as Autistic Spectrum Disorders and include: Autism, Asperger's Disorder, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Developmental Disorder (Not Otherwise Specified) (Klinger & Dawson, 1996). According to Szatmari (1996), the other Autistic Spectrum Disorders differ from autism in that they lack specific types of behaviors, have fewer symptoms, and have a different age of onset and course. However, debate on the qualitative differences between particular Pervasive Developmental Disorders continues to exist as current research suggests few substantive distinctions between high-functioning autism and Asperger's Syndrome (Lord & Rutter, 1994).

Associated Disorders

Present research indicates that 75% of the autistic population presents with some degree of mental retardation (Volkmar et al., 1997). Autism has also been associated with a number of disorders of childhood such as developmental language disorders (Cicchetti & Cohen, 1995), Tourette's Disorder (Wing, 1997), and obsessive-compulsive disorder (Wing, 1997). Furthermore, medical syndromes related with autism include: phenylketonuria (PKU) (Folstein & Rutter, 1987), Fragile X syndrome (Bolton et al., 1991; Rutter et al., 1993), Landau-Kleffner

syndrome (Wolf-Schein, 1996), tuberous sclerosis (Gutierrez, Smalley, & Tanguay, 1998; Smalley 1992;), neuronal ceroid lipofuscinosis (Taft, 1993), Lesch-Nyhan syndrome (Taft, 1993), hypsarrhythmia or infantile spasms (Taft, 1993), lactic acidosis (Coleman & Blass, 1985), Duchenne muscular dystrophia (Komoto et al., 1984), Williams syndrome (Reiss et al., 1985), asthma (Baron & Dondey, 1993), recurrent ear infections (Crook, 1998) and epilepsy (Wong, 1993; Gillberg, 1991).

Epidemiology

“Epidemiological research serves both practical and theoretical purposes. It not only reveals the prevalence of a disorder, but also its course, outcome, and occasionally information regarding the underlying etiology and neuropsychopathology” (Bryson, 1997, p 41).

Epidemiological studies estimate the prevalence of autism to be 2-5 per 10,000 individuals (APA, 1994). The Autism Society of America (1995) reports that Autistic Disorder occurs in approximately 15 out of every 10,000 births. More recent work estimates the prevalence rate of autism at 10 cases per 10,000 (Volkmar et al., 1997). According to Wolf-Schein (1996), prevalence rates vary according to the definition employed. Fombonne (1997) recently determined the prevalence rates to vary from 0.7-15.5 per 10,000, depending on whether the entire “autistic spectrum” is included or not.

Gender Differences

According to Dawson and Klinger (1996), three to five times more males to females are affected with autism. Taylor and Ounsted (1972) delineated that with uneven sex ratios, the lower prevalence sex tends to be relatively more severe. As such, girls are more likely than boys to have a more severe form of autism (Cicchetti & Cohen, 1995). Konstantareas, Homatidis, and Busch (1989) reported that nonverbal IQ and mental age tend to be higher in autistic males.

In addition, boys with autism tend to evidence superior performance in the areas of operational causality, object permanence, receptive language, peer interaction, imitation of invisible movement and unfamiliar configurations, and the ability to verbalize. Additionally, Bryson, Clark, and Smith (1988) reported that none of the girls in their study demonstrated an IQ of more than 70. Others have documented that among the severely mentally retarded children with autism, girls are almost as frequent as boys, yet “high-functioning” girls are exceedingly rare (Steffenburg & Gillberg, 1989 ;Tsai & Beisler, 1983; Tsai et al., 1981). Taken together, the empirical evidence supports the relationship between gender and the severity of autism.

Etiology

Autism is a behavioral disorder of unknown etiology (Piven et al., 1993). Because the syndrome is defined by history, onset, and behavioral criteria, it has been thought of as an etiologically heterogeneous disorder (Campbell & Green, 1985; Coleman & Gillberg, 1985). Moreover, it has been demonstrated that no single theory has the explanatory power necessary to address the complexity of the disorder. To date, a single causal pathway has not been discovered (Dawson, 1992). However, possible genetic, pre-, peri-, and neonatal complications, biological and neurological explanations of the disorder, as well as psychodynamic theories of its origin, have been postulated (Klinger & Dawson, 1996).

Genetic explanations. Both twin and family studies suggest that genetic factors play a considerable role in the etiology of autism (Wenar, 1994). According to Baron-Cohen (1995), the risk for autism increases substantially in identical twins and biologically related siblings. In epidemiological studies of siblings, the pooled frequency of autistic disorder was approximately 3%, which is 50 times greater than the expected prevalence rate (Popper & Steingard, 1996; Smalley, Asarnow, & Spence, 1988). According to Popper and Steingard (1996), about 5% to

25% of siblings of autistic individuals evidence delays in learning, usually associated with language and speech, mental retardation, or physical defects. Family studies also indicate that autosomal recessive inheritance may exist for certain cases of autism (Popper & Steingard, 1996).

Chromosomal abnormalities resulting in several specific genetic disorders have also been associated with autism (Yeung-Courchesne & Courchesne, 1997). Fragile X syndrome, tuberous sclerosis, and phenylketonuria (PKU) are three genetic disorders, which have been reported as co-occurring with autism. Fragile X syndrome has been found in approximately 8% of individuals with autism (Smalley, Asarnow, & Spence, 1988). The rates of other disorders such as tuberous sclerosis, and (PKU) are also quite minimal (Folstein & Rutter, 1987) and therefore cannot account for the etiology of autism. On the whole, what remains to be determined is which aspects of autism are heritable and how the genetic information is translated into autistic behavior (Wenar, 1994).

Pre-, peri-, and neonatal complications. A number of studies have shown a relationship between pre-, peri-, and neonatal factors and autism. Significant associations have been made regarding a higher-than-expected number of risk factors contributing to those infants later diagnosed with autism (Dawson, 1992; Tsai, 1987). However, problems evident at birth are more firmly related to problems in the fetus, rather than to labor and delivery complications (Volkmar et al., 1997). Tsai (1987) determined that bleeding after the first trimester, use of prescription medication, meconium in the amniotic fluid, and a maternal age greater than 35 years were seen significantly more frequently in children with autism as compared to normal developing controls. Other researchers have found differing results, demonstrating that only the gestation age greater than 42 weeks and birth order (i.e. first, fourth, or later than fourth) were

associated with autism (Lord et al., 1991). Furthermore, neonatal convulsions and other biological hazards carrying the potential risk of brain damage have been shown to differentiate autistic children from their nonautistic twins (Wenar, 1994). Taken together, these results demonstrate that pre-, peri-, and neonatal factors associated with autism are relatively unspecific and of uncertain significance (Rutter, Macdonald, le Couteur, & Harrington, 1990).

Biological explanations. Kanner (1943) suggested that autism was an endogenous form of psychopathology, brought about by deficiencies in the biological systems responsible for the regulation of affective contact with others. He also proposed that children with autism suffered from a biologically based disorder of affective systems, which resulted in severely disturbed patterns of social development. At present, research continues to focus on neurobiological theories of autism and autistic-like conditions (Gillberg, 1990).

Arguments continue to be made for probable differences in the neurobiology and biochemistry of children with autism (Fein, Pennington, & Waterhouse, 1989). Researchers have examined serotonin, dopamine, norepinephrine, brain opioids, peptides, and other compounds in individuals with autism (Yeung-Courchesne & Courchesne, 1997). Compared to controls, autistic samples tend to evidence elevated serotonin levels, monoaminergic system and opioid functioning abnormalities, abnormal plasma B-endorphin levels, elevated T3 and T4 levels, and unmodulated plasma growth hormone responses to insulin-induced hypoglycemia (Yeung-Courchesne & Courchesne, 1997). However, consistent results across studies have not yet been attained (Volkmar & Anderson, 1989).

Neurological explanations. Rimland (1964) and Schopler (1971) were the first researchers to postulated a neurological impairment as a potential etiology of the disorder. Presently, neuroanatomical findings suggest potential differences in particular areas of the brain

such as an enlargement of the fourth ventricle, (Gaffney, Kuperman, Tsai, & Minchin, 1987), diminished cerebellum size (Courchesne et al., 1988), abnormal EEG patterns (Yeung-Courchesne & Courchesne, 1997), and hyper-or hypofrontality, atypical asymmetries in temporal and frontal lobes and basal ganglia (Buchsbaum, Siegel, Wu, Hazlett, Sicotte, Haier, Tanguay, Asarnow, Cadorette, Donoghue, Lagunas-Solar, Lott, Paek, & Sabalesky, 1992). Malfunctions of the cerebral cortex (Yeung-Courchesne, 1993; Piven, 1990) have also been identified. In addition, autopsies of children with autism have revealed abnormal cerebellum development (Ritvo, 1986). However, results have rarely been replicated and consistent patterns of neuropathology have not been achieved (Wenar, 1994).

Psychological explanations. Other theories regarding the “cause” of autism have suggested the existences of parental psychopathology or what Bettelheim (1967) termed as “the refrigerator mother”. To be more specific, Bettelheim (1967) proposed that children with autism, in response to rejecting parents (typically mothers), withdrew from social interaction. According to Bettelheim (1967), “autism has essentially to do with everything that happens from birth on” (p. 393). That is, he believed that autism typically arose on the basis of maternal rejection. Furthermore, Tinbergen and Tinbergen (1983) suggested that autism was caused by an “anxiety dominated emotional imbalance”, leading to social withdrawal and the inability to learn from social interaction. Tinbergen and Tinbergen (1983) was also suggested that this imbalance was a result of a lack of bonding between mother and child.

Given the lack of empirical support, these psychodynamic explanations of causation were subsequently rejected (Klinger & Dawson, 1996). Although it is true that abnormalities in child rearing may lead to difficulties in social behavior, the nature of the social abnormalities found in

children with autism do not resemble those identified in normative samples or other clinical populations (Rutter & Schopler, 1987).

In summary, it is clear that a number of factors may play a role in the etiology of autism. However, biological factors appear to play a significant, and perhaps even dominant role in the pathogenesis of autism (Cammisa & Hobbs, 1993). However, there is little consensus regarding which factors play the most important role and whether it is even plausible to attribute a causal role to any factor or set of factors (Cammisa & Hobbs, 1993).

Course of Autism

There has been relatively little research, which has examined the natural course of autism. The general progression of the disorder is gradual, yet there is a high degree of irregularity in the speed of change (Popper & Steingard, 1996). According to Rapin (1997), some individuals with autism improve substantially when they acquire language skills and learn to use these skills to communicate their needs and to influence others. In some cases, behavior deteriorates during the adolescent years, and may reflect the effects of hormonal changes, depression, or the greater behavioral demands associated with the complex adolescent social world (Gillberg, 1992). Further, episodes of overt aggression may occur during periods of environmental stress or recurrent medical illness, as well as during periods of rapid development (Popper & Steingard, 1996).

Only a small minority of those with autism progress to the point that they are able to lead productive, self supporting lives, while the majority remain relatively dependent (Rapin, 1997).

• According to Spiker, Lotspeich, and Kraemar (1994), social skills rarely improve to the degree that permits successful marriage, yet those mildly affected do occasionally marry and have children.

Intervention

Given the severity of the disorder, it is not surprising that a wide variety of treatments have been utilized including: dietary interventions; megavitamins; educational interventions; Sensory Integration (Ayres, 1972); Auditory Integration Therapy (Stehli, 1991); pharmacological treatments; and behavioral psychotherapy (Lovaas, 1987; Olley, Robbins, & Morelli-Robbins, 1993). At present, the best available evidence directs researchers and practitioners to the importance of appropriate structured educational interventions to foster the acquisition of basic communicative, social, and cognitive skills (Volkmar et al., 1997).

At this point, it is important to consider the specific deficits associated with autism. Research has consistently demonstrated that autistic individuals display qualitative impairments in the collective triad of cognitive abilities, language skills, and social abilities. Moreover, there is empirical evidence of the repetitive behaviors and restricted interests associated with the syndrome. In the sections which follow, the deficits associated with autism will be examined in detail.

Deficits Associated with Autism

Cognitive Abnormalities

Kanner (1943) initially suggested that children with autism exhibited normal levels of intelligence because of their relatively superior performance on certain parts of traditional tests of intelligence (Volkmar et al., 1997). The assumption was then made that if these children could score in the normative range on specific subsets, and were motivated to do so, they would also be able to evidence normal performance on other areas of the IQ test. Subsequently, homogeneity in cognitive ability was believed to exist in autistic individuals (Szatmari, 1996).

The assumption of cognitive homogeneity was later refuted by researchers who demonstrated that tests administered according to the child's overall level of functioning, rather than just to the child's chronological age, were reliable measures, predictive of ultimate outcome (Klin & Shepard, 1994; Lockyer & Rutter, 1969). Thus, Kanner's (1943) assertion that children with autism had a normal cognitive potential was demonstrated to be inaccurate (Volkmar, 1997; Rutter & Schopler, 1987).

Following Kanner's assertions, it was suggested that autistic individuals experienced difficulties with higher-order thinking. For instance, Piaget suggested that children with autism had difficulties with assimilation. That is, he suggested that they were not able to relate new information to past experiences. As such, they tended to "echo" rather than understand (Wenar, 1994). Consequently, Piaget delineated that autistic thought processes were concrete and situation specific. Others (e.g. Dawson, 1992) have postulated that autistic individuals have difficulty coding and organizing stimuli. Dawson (1992) demonstrated that children with autism have perceptual processing deficits, which prevent them from effectively completing such tasks. According to Frith and Baron-Cohen (1987), autistic children attempt to compensate for their coding and organization deficits by engaging in stereotyped behaviors (i.e. to establish stability and predictability in a significantly overwhelming environment). Moreover, children with autism tend to use a rule-based approach when presented with tasks involving categorization (i.e. all fish have short tails). To be more specific, they do not appear to use a summary representation or prototype approach to categorization (Klinger & Dawson, 1996).

Difficulties with verbal and nonverbal symbols also pose challenges to the autistic child. According to Wenar (1994), the important functions of symbolization are as follows: 1) symbolization allows the child to be released from a reliance on action; for instance "the act of

walking up the stairs can be represented by the thought “I can walk upstairs.” 2) symbolization replaces trial-and-error behavior; and 3) symbolization opens the door to abstractions that have no specific referent in concrete reality, such as “right” and “wrong.” In terms of symbolic play, clear differences exist between autistic children and age-matched groups of normally developing peers in both highly structured play interactions and free play activities (Dawson, 1992). For instance, Sigman and Ungerer (1984) demonstrated that the functional play and free play behaviors of children with autism were less diverse than those of typical peers. Differing from mentally retarded children, children with autism were unable to utilize a doll as an independent agent of action (i.e. to attribute animate characteristics to the doll) (Dawson, 1992).

Lastly, another specific cognitive deficit associated with autism is the failure to develop the ability to “predict and explain the behavior of other humans in terms of their mental states” (Cicchetti & Cohen, 1995, p 363). The ‘theory-of-mind’ hypothesis (Baron-Cohen, 1985) postulates that children with autism are specifically impaired in their ability to understand that other people have desires, beliefs, and intentions that are different from their own. According to Happe (1997), this impairment negatively impacts the developing child’s imagination, communication, and social abilities. Similarly, Baron-Cohen (1985) theorized that a core metarepresentational deficit (i.e. a lack of awareness of the intentional relations between other people and the world; Dawson, 1989) was responsible for communication and social deficits observed in autism.

According to Klinger and Dawson (1996), the memory impairments of autistic individuals tend to vary, depending on their level of functioning. For high-functioning individuals, impairments are typically observed on tasks which require long-term memory, abstract thought, and/or the ability to attain strategies for encoding complex information. The

areas of impairment in low-functioning individuals include short and long-term memory and declarative memory (Klinger & Dawson, 1996). Furthermore, DeLong (1992) suggested that the memory deficit in autism was a result of an impairment in memory management precipitated by hippocampal damage. The results of such a deficit, according to DeLong (1992), limit the individual with autism to stimulus-response type behaviors, as access to memory systems is cut off.

Some researchers also report that individuals with autism do not suffer from gross memory deficits (Sigman, 1989). That is, there is empirical support that individuals with autism exhibit adequate memory functioning in some areas. Such areas include: visuospatial organization, sustained attention, paired associate learning, auditory rote memory, cued recall, discriminate learning, and operant learning (Klinger & Dawson, 1996).

Lastly, impairments in executive functioning have also been revealed in the autistic literature. According to Rapin (1997) executive function is “the ability to consider alternatives in planning” (p. 856). Executive functioning requires a variety of skills including the ability to: keep a number of items in working memory, allocate attention to competing stimuli, balance priorities, weigh the consequences of alternative courses of action, consider available resources realistically, and think of possible options before taking action (Rapin, 1997). Research has consistently demonstrated that individuals with autism display impaired performance on executive-function tasks (Klinger & Dawson, 1996).

In summary, the cognitive abnormalities associated with autism are extensive and complex (Dawson, 1992). Although some specific memory systems are intact (e.g. auditory rote memory), and even phenomenal in some cases, difficulties with symbolic play, the

comprehension of abstract concepts, and theoretical understanding are commonly observed (Barker, 1994).

Social Abnormalities

Social unrelatedness is considered the hallmark of autistic disorder (Fein, Pennington, & Waterhouse, 1987). Hobson (1989) proposed that children with autism are profoundly impaired in their personal relations. Although they are often the most handicapping of the core impairments, the social deficits associated with autism have been the least documented (Lord, 1993). In the social domain, impairments in social imitation, emotional perception, attachment, and social cognition have been reported (Klinger & Dawson, 1996).

It has been suggested that children with autism have a specific impairment in their ability to imitate the behavior of others in their environment (Sigman and Ungerer, 1984b). To be more specific, difficulties with motor and vocal imitation has been well documented in the literature (Lord, 1993). Smith and Bryson (1994) suggested that the imitative delays observed in autistic individuals may be due to their incapacity to perceive and represent events. Others have proposed that the imitative deficits of autistic children may interfere with the development of other critical social skills such as joint attention, reciprocity, and the understanding of emotional states (Dawson, 1991; Meltzoff & Gopnik, 1993).

In reference to emotion and affect, there is much research to support the notion that normally developed infants appear to be preprogrammed to recognize emotions in others, and to use emotion as an early form of communication. In contrast to normal infants, children with autism appear to view the world of emotions as foreign (Walters, Barrett, & Feinstein, 1990). According to Sigman and Mundy (1987), positive affect is not displayed as frequently by children with autism. Dawson (1990) also suggested that autistic children are less likely to

combine smiling with eye contact, and are less likely to smile in response to a mother's smile. Other studies, which examined the ability of autistic individuals to match photos on the basis of facial affect (Fein & Waterhouse, 1987) have also demonstrated deficits in emotional understanding. Contributing to abnormalities in affect are the impairments in eye gaze, joint attention, and the desire to attract other's attention (Sigman, 1989). Taken together, these findings suggest that autistic individuals are impaired in both their ability to produce and their ability to understand emotional expression.

More recently, researchers have begun to examine attachment in children with autism. Originally, it was assumed that children with autism did not form attachments to their primary caregivers (Klinger & Dawson, 1996). For instance, Cohen, Paul, and Volkmar (1987) demonstrated that autistic children were not able to discriminate between familiar and unfamiliar adults. Nonetheless, other researchers have found that children with autism do show differential responses to primary caregivers (Dissanayake & Crossley, 1997; Shapiro, Sherman, Calamari, & Koch, 1987; Sigman & Mundy, 1989; Sigman & Ungerer, 1984a). For example, Sigman and Mundy (1989) found that autistic and mentally retarded children behaved in a similar fashion when separated from, and reunited with, their primary caregivers. That is, both groups directed more social behaviors to their caregivers than to strangers and increased their preferential behavior after separation.

Researchers have also examined the quality of the attachments formed by children with autism. In recent years, the quality of attachment relationships has been measured through the utilization of Ainsworth, Blehar, Waters, and Wall (1978) classification system of attachment patterns. This classification system attempts to incorporate, not only normative samples of children and their dyadic attachment relationships, but also provides a pattern of attachment

which has been identified in more clinical populations (i.e. Type D) (Main & Solomon, 1990). The primary characteristic of the Type D attachment style, which is thought to be a form of insecure attachment, is characterized by disorganized coping mechanisms displayed in contradictory behavior patterns (Cicchetti, Toth, & Lynch, 1995). Capps, Sigman, and Mundy (1994) demonstrated that disoriented and disorganized behaviors were displayed by their sample of children with autism. Other researchers have demonstrated that children with autism display attachment styles similar to a normative age-matched population if the autistic behaviors are ignored, although the development of secure attachment may be delayed and alter the behavioral patterns that express attachment security (Rogers, Ozonoff, & Maslin-Cole, 1993). Nonetheless, various methodological issues complicate the interpretation of such empirical findings. For instance, the comparison groups utilized did not display the multiple handicaps in social, cognitive, language and behavioral development consistent with autism (Rogers, Ozonoff, & Maslin-Cole, 1991). Even psychiatric control groups fail to demonstrate the range of deficits displayed by the autistic population. Therefore, the uniqueness of this developmental disorder makes comparisons to other groups challenging.

Contrary to the findings of Dissanayake and Crossley (1997), Shapiro et al., (1987), Sigman and Mundy (1989), and Sigman and Ungerer (1984a), other empirical studies have failed to demonstrate that autistic individuals display secure patterns of attachment. Instead, some researchers have suggested that differential proximity seeking should be viewed only as a primitive element of attachment (Dawson, 1989). According to Dawson (1989) proximity to a parent may also be partly due to a familiar and predictable social interaction, resulting in considerably more simplistic attachment patterns than accounted for by traditional classification of attachment behaviors. Hence, the research appears to suggest that children with autism are

able to form attachments, but have significant difficulties understanding and responding to social information (Sigman & Mundy, 1989).

As mentioned earlier, the cognitive deficits associated with autism are thought to be directly related to the social abnormalities which are observed (Walters, Barrett, & Feinstein, 1990). According to Shah and Wing (1986), the social deficits in autism tend to be a function of the level of cognitive functioning. Similarly, Sigman et al., (1987) postulated that the inability to transform information to a symbolic level may derive from a lack of social interest. It has also been suggested that the autistic child's inability to encode meaningful stimuli, a failure to take meaningful context into account, a lack of inner language, and lack of internal conceptual structures (Walters, Barrett, & Feinstein, 1990) contributes to their social difficulties.

In sum, severe social abnormalities exist in children with autism. These abnormalities (i.e. social imitation, emotional perception, attachment and social cognition) are viewed as central to the disorder (Bacon, Fein, Morris, Waterhouse, & Allen, 1998). Considering that autism represents a fundamental failure in social relatedness, research continues to elucidate the nature of the deficit and to account for the complex interplay observed between social, cognitive, and communicative deficits (Grossman, Carter, & Volkmar, 1997)

Language Abnormalities

Profound abnormalities in the development of communication skills and language abilities are a critical feature of autism (Pennington & Welsch, 1995; Mundy, 1987).

Difficulties with speech and language are marked by numerous deviancies in language such as echolalia, abnormal prosody, and pronoun reversal (Wenar, 1994). As well, approximately half of all autistic children remain mute throughout their life span (Klinger & Dawson, 1996).

Moreover, those who do develop oral language and/or conventional methods of nonverbal

communication, generally continue to display delayed and/or deviant language abilities (Dawson, 1992). In addition, children with autism differ in the quality and rate of their language development (Rutter, 1967).

According to Pennington and Welsch (1995), children with autism often fail to demonstrate communicative intent (i.e. the ability to use language for intentional purposes). Also, impairments in the early development of joint attention and symbolic play significantly impact communicative development as both of these behaviors are considered to be precursors to language development (Klinger & Dawson, 1996). Limited flexibility in play and imagination may also relate contribute to the autistic language deficits seen in autism (Wing, 1981). Likewise, failing to develop normal verbal and nonverbal (i.e. body language, gestures, facial expressions, eye-to-eye gaze) methods of communication extremely limits the autistic child's ability to express their thoughts and needs to others.

Geller (1998) suggested that a communication breakdown exists in children with autism. To be more specific, he postulated the existence of a breakdown in the speaker's response to the listener's request for clarification of his/her original message. Geller (1998) stated that the challenging issue in childhood autism is "to understand the synergistic relationship within and across social-cognitive domains... delays or difficulties in each domain of language clearly influence children's display of knowledge and effectiveness in responding to a listeners needs" (Geller, 1998, p. 82). In general, the primary function of language is to mediate social interaction. However, given that the defining feature of autism is deviant social interaction, the vehicle of language is greatly hindered in the processes of functional communication (Pennington & Welsch, 1997).

Repetitive and Stereotyped Behaviors and Interests

It has been demonstrated that children with autism often engage in abnormal, repetitive behaviors and display restricted interests (Klinger & Dawson, 1996). According to the DSM-IV (American Psychological Association, 1994), these stereotyped patterns of behaviors, interests and activities are manifested by: preoccupations with a particular pattern of interest that is abnormal in either intensity or focus, an inflexible adherence to specific, nonfunctional routines or rituals, stereotyped and repetitive motor mannerisms, or a persistent preoccupation with specific parts of objects.

McBride and Panksepp (1995) defined stereotyped behaviors as non-functional, repetitious, self-stimulatory body movements. These behaviors are typically subsumed under such terms as “restricted range of interests” or “insistence on sameness” and encompass a diverse group of behavioral features (Volkmar, 1996). The most commonly reported repetitive behaviors include body rocking, swaying, toe-walking, hand, finger or arm flapping, and whirling (Wenar, 1994). According to Nijhof, Joha, and Pekelharing (1998), these behaviors differ from compulsive behaviors in that they lack purpose. Furthermore, in terms of repetitive interests, Klinger and Dawson (1996) report that perseverative interests typically involve memorization of facts about a specific subject area (e.g., the solar systems).

Summary

Autism has been identified as the most severe developmental disorder of childhood (Volkmar, 1997; Baron-Cohen, 1995; Wenar, 1994) and is characterized by impairments in the development of speech and language skills, cognitive abilities, social skills, as well as by a restricted repertoire of interests and behaviors (Klinger & Dawson, 1996). The prevalence of autism is approximately 2-5 per 10, 000 (Volkmar, 1997) and varying theories exist regarding

the etiology of autism. Moreover, associated medical and psychological conditions are also known to concurrently exist with the disorder. The course of autism is progressive, yet irregular. Treatment for autism has produced varying results. According to Dawson (1992), autism remains a puzzling disorder, as wide differences exist in severity and symptomatology.

Now that the deficits associated with autism have been outlined, the issues of prognosis and outcome will be discussed. More specifically, potential prognostic variables will be examined. Following this, the present study will be described in detail.

Chapter Two

Prognosis and Outcome

A Historical Overview

The issue of prognosis in autism was first addressed by Lotter (1974), who began by examining the factors related to outcome. Four years later, Lotter reviewed all the studies which had addressed outcome in autism and categorized outcome using the following hierarchy: good (normal or near normal social life and satisfactory functioning at school or work); fair (some social and educational functioning, despite significant abnormalities in interpersonal relationships or behavior); poor (i.e. no independent social progress and severe handicap), and very poor (i.e., inability to lead any sort of independent existence). Five to seventeen percent of Lotter's (1978) research sample was reported to fall into the good outcome category.

Furthermore, Gillberg and Steffenburg (1987) introduced a fifth outcome category between Lotter's fair and poor, termed "restricted but acceptable outcome." This group referred to those in the poor group who had been accepted by a peer group to the extent that their handicaps were not so apparently obvious (Gillberg & Steffenburg, 1987).

Other researchers, utilizing cognitively heterogeneous samples, have found higher rates of favorable prognosis than those previously reported by Lotter (1978). For instance, Chung, Luk, and Lee (1990) and Gillberg and Steffenberg (1987) found that 4-32% of their autistic samples displayed "good" outcome. Even though more recent follow-up studies have suggested better prognosis in children with autism, it is evident that autism continues to be associated with a variable course and prognosis (Gillberg, 1991).

Specific Prognostic Variables

Many researchers have attempted to identify the specific variables which impact the course of the disorder. These variables include: language abilities, intelligence, social interaction skills, the presence of comorbid illnesses, the age at which developmental milestones are achieved, the age at which the individual is diagnosed, the age at which treatment is initiated, and family factors (e.g. family composition).

Language Abilities

According to Lotter (1974; 1978), the presence of functional language by age five was one of the most potent predictors of outcome in individuals with autism. Consistent with this research, Lord and Paul (1997) reported that achievement of useful expressive language by the age of five years was the most powerful predictor of both behavioral and vocational outcome. Moreover, Shapiro (1992) stated that, “if communicative speech is developed by the age of five, there is a 50% chance for some social recovery” (p. 357). Fluency and flexibility of expressive language have also been found to discriminate between high and low-functioning individuals with autism (Lord & Paul, 1997). Further, Popper and Steingard (1996) reported that increases in language skills, particularly in vocabulary, were associated with better prognosis.

In examining language abilities, it is also important to examine progress in communication skills in relation to prognosis. According to Dawson (1992), considerable gains in language abilities can affect cognitive, social and behavioral skills. Therefore, progress in relation to communication should be regarded in reference to better outcome in children with autism. According to Prizant and Schuler (1987), progress in communication needs to be conceptualized in the acquisition of communicative abilities. Thus, in relation to prognosis, it

appears necessary to examine the communicative gains of an individual with autism, as well as the age of language development.

Intelligence

It has been demonstrated that measured intelligence (i.e. IQ) is a powerful predictor of prognosis in autism. Waterhouse, Wing, and Fein (1989) delineated that it is often the case that autistic children with higher IQs have a generally better prognosis, than do children with lower IQs; however, this does not necessarily mean that there are two IQ separable subgroups (i.e. above or below an IQ of 50) of children with autism. It only suggests that “being in the top half of the IQ distribution is beneficent for later outcome” (Waterhouse et al., p. 269). In addition, Stone, MacLean, and Hogan (1995) reported that higher functioning individuals (i.e. IQ > 60) achieve more favorable outcomes.

IQ has also been found to be related to the presence of useful speech before the age of five (Lotter, 1978). The lower the IQ (i.e. the more severe the mental retardation), the less likely the autistic child is to develop speech. According to Lotter (1978) lower IQ is associated with a “a lesser likelihood of developing useful speech and a poor outcome.” (p. 483). In addition, Lotter (1978) suggested that a combination of speech and IQ may be more useful when exploring prognosis rather than examining each variable separately. It is also important to note that Volkmar (1996) indicated that the importance of IQ to outcome is not specific to the autistic population. IQ is also critical in other forms of child psychopathology (e.g., mental retardation, developmental disorders).

Measured intelligence in individuals with autism has also been examined in relation to the severity of the disorder and the level of adaptive functioning. According to Lotter (1974), severity was significantly associated with IQ and ranked high as a factor related to outcome.

More recent studies have also generally found severity of autism, IQ, and adaptive functioning to be closely related. Rumsey, Rapoport, and Sceery (1985) determined that adaptive functioning increased with IQ. However, Schatz and Hamdan-Allen (1995) were unable to significantly support these findings. Thus, it appears that IQ may be closely associated with severity, but the extent to which IQ is associated with adaptive functioning in autism is yet to be determined.

Social Interaction

Level of social interest and ability to interact with others also appears to be associated with outcome in autism (Volkmar, 1996). According to Volkmar, Carter, Grossman, and Klin (1996), styles of interaction are closely related to developmental level. Lord (1993) examined the social skills of autistic children over several years and found that the social deficits tended to improve as chronological age increased.

Also, Wing and Gould (1979) categorized autistic children into three groups based on their socialization abilities. These descriptive classifications were described as “aloof”, “passive”, or “active-odd”. The “aloof” group was characterized by children who did not initiate interactions with others and who reacted negatively when others attempted to initiate interactions with them. The “passive” group included children who were receptive when others attempted to interact with them, but did not initiate social interactions on their own. Finally, the “active-odd” group initiated social interaction, but did so in an odd or idiosyncratic manner. Wing and Gould (1979) found that the “aloof” group was associated with lower cognitive abilities and more severe cognitive impairments. Further, it was noted that autistic children tended to evidence social gains as they grow older. To be more specific, it was found that aloof children tended to progress to being passive or active-odd. Moreover, it was noted that regression within the social domain was rare. That is, autistic children do not typically move

from being passive to aloof. Thus, there is some empirical evidence to support the contention that socialization abilities are associated with outcome in autism (Popper & Steingard, 1996).

Comorbid Medical Illness

The issue of comorbidity and autism has become increasingly important in recent years (Volkmar, Klin & Cohen, 1997). With any serious disability, such as autism, comorbid medical illnesses seem to increase the risk for other problems (Volkmar, Klin & Cohen, 1997). For instance, Rapin (1997) reported that approximately 10 percent of children with autism are found to have an EEG pattern of the type seen in Landau-Kleffner syndrome, an acquired epileptic aphasia. This EEG pattern, as also seen in individuals with disintegrative disorder, has been associated with a particularly poor outcome (Rapin, 1997). As well, early onset seizures and adolescent onset seizures have also been associated with autism (Wong, 1993; Gillberg, 1990). Individuals with such comorbidity have been documented as having a poorer outcome (Gillberg, 1990).

Another example of the relationship between comorbidity of medical illness in autism and prognosis is neuronal ceroid lipofuscinosis, a neurodegenerative disorder of childhood. Infants with this disorder develop seizures, visual failure, and a delay in the growth of the head. Prognosis in these children is extremely poor. According to Taft (1993), “most children continue to regress in motor skills, and after a few years, are in a vegetative state intellectually.” (p 182). Given that neuronal ceroid lipofuscinosis is associated with autism, it appears likely that children with such comorbidity have an increased likelihood of poorer prognosis. Therefore, with the number of associated medical conditions linked with autism, it appears logical to explore the prognosis of autistic children with comorbid medical illness versus those who do not present with additional medical ailments.

Age of Developmental Milestones

Given that autism is one of the most severe “developmental” disorders of childhood, it is not surprising that developmental milestones are achieved in a delayed or deviant fashion (Wenar, 1994). As previously reported, the acquisition of language before the age of five years appears to be one of the greatest developmental markers and potentially powerful prognostic factors. According to Wenar (1994) delays and deviations exist in milestones related to both social behavior and self-concept, perception, attention, higher-order thinking, and language. For instance, in the area of social behavior, developmental lags or deviancies existed in the autistic child’s imperviousness to the social environment, gaze, display of positive affect, vocalization, imitation, initiative, reciprocity, attachment, play and compliance and negativism. In terms of self-concept, self-recognition and positive affect or coyness were also found to be developmentally delayed or deviant.

Unfortunately, the relationship between prognosis and other developmental milestones has been relatively ignored in the empirical literature. However, although not specific to autism, Favata, Leuzzi, and Curatolo (1987) explored four developmental milestones in a population of children with West syndrome, an epileptic encephalopathy of early infancy as related to intellectual outcome. Sitting unsupported, walking without aid, uttering the first specific word, and using a sentence of two words were explored in relation to prognosis. It was found that the age of motor milestones (i.e. sitting and walking without support) was not predictive of intellectual outcome, but that speech development was significantly related to prognosis. That is, the gap between the age of first word and the age at which a two-word sentence was formed increased as IQ lowered. Given that epilepsy has been associated with autism, it is fair to

suppose that the results of Favata et al (1987) could be regarded as somewhat informative in relation to developmental milestones in an autistic population.

Early Diagnosis and Intervention

According to Klinger and Dawson (1996), early diagnosis is associated with more positive outcomes in individuals with autism. This contention has also been voiced by Freeman (1997) and Porter, Golstein and Carel (1992). Moreover, it is commonly believed that “early diagnosis is essential because it allows for earlier intervention” (Klinger & Dawson, 1996). For example, Fenske, Zalenski, Krantz, and McClannahan (1985) compared the progress of nine children who began intensive behavioral treatment before age five with those who entered the intervention program after age five. Both groups were determined to exhibit comparable levels of autistic behavior prior to treatment. It was found that, out of the nine children who began treatment before the age of five, six made considerable progress. Only one out of the nine children in the comparison group made comparable gains. Similarly, Lovaas, (1987) reported that approximately half of the 19 children who initiated an intensive early intervention program of 40 hours a week before age 4 (i.e. 47%) achieved normal intellectual and educational functioning, with normal-range IQ scores and successful first grade performance in public schools. Another 40% were mildly retarded and assigned to special classes for the language delayed, and only 10% were profoundly retarded and assigned to classes for the autistic/retarded. Conversely, out of the children from the control group of 40 who received less than 10 hours a week, only one child achieved similar gains.

Early intervention is based upon the belief that children with developmental disabilities are most responsive to treatment when they are very young (Guralnick, 1991). According to Dunlap and Fox (1996), “early intervention and behavioral support programs can result in: a)

changes in the individuals' social relationships and daily activity patterns, b) increases in community inclusion, c) changes in the individuals' health status or need for crisis intervention, d) an expansion of skill repertoires, and e) a generalized reduction in problem behavior" (p. 33).

Given the importance of early diagnosis and intervention, it is critical that researchers identify the characteristics displayed by infant and toddlers with autism. Some researchers have suggested that deficits in symbol activities (i.e. symbolic play deficits and deficits in joint attention) are the first identifiable manifestations of the disorder (Baron-Cohen & Gillberg, 1992). According to Dawson and Osterling (1996), "one of the more exciting recent achievements in the field of autism is the ability to recognize the disorder at a very early age" (p. 307). More specifically, it has been found that autism may be diagnosed as early as 18 months of age. Recently, Baron-Cohen, Allen, and Gillberg (1992) developed an instrument for the early screening of autism called the Checklist for Autism in Toddlers (i.e. the CHAT). In 1996, Baron-Cohen, Cox, Baird, Sweetenham, and Nightingale utilized the CHAT in a large sample. That is, sixteen thousand children were screened with the CHAT during an 18-month routine developmental checkup. It was found that 12 children failed the CHAT items, which required protodeclarative pointing, gaze-monitoring, and pretend play. Of these 12, ten were subsequently diagnosed with autism. When these ten children were reassessed at three and a half years of age, their diagnosis of autism was maintained.

Taken together, it is evident that there exists substantial empirical support for the early identification and treatment of autism. In terms of prognosis, the current literature appears to support the notion that early diagnosis and treatment may lead to better outcome.

Family Variables

Family issues may also impact prognosis in autism. Harris (1994) reported that the manner in which a family responds to a child with autism has the potential to influence both the child's manifestation of behavior problems and the child's educational gains. According to Paul (1987), the presence and involvement of family members would appear to be logically related to outcome. Having a dysfunctional and disorganized family, or a clinically depressed parent may also create stress for the autistic individual in that it has the potential to lead to chaos in the home environment (Harris, 1994).

Stressful events may also create challenging conditions for a child with autism. For instance, divorce is a stressful experience for any child, which is usually preceded, and often followed by a period of interpersonal conflict (Wolchik, Sander, Braver, & Fogas, 1985). The Amato and Keith (1991) meta-analysis highlighted the negative impact of parental conflict on developing children. Interpersonal hostility creates an aversive home environment in which children experience unhappiness and insecurity (Maccoby & Martin, 1983). Conflict is also likely to place stress on parents and make them less effective in dealing with their children (Hetherington, Cox, & Cox, 1982; Wallerstein & Kelly, 1980). Furthermore, stressful events, such as divorce may disrupt children's school achievement, social relationships, and personality development, all of which have long-lasting implications (Amato & Keith, 1991).

Conversely, the stress associated with caring for a child with autism has the potential to impact family functioning. According to Sanders and Morgan (1997), "a child with a severe handicap can have a profound impact on the family" (p 16). Such effects are not unidimensional, but multifaceted and reciprocal, altering the family unit as a whole (Harris, 1982). Chronic psychological stress is also hypothesized to manifest itself in family difficulties (Koegel

Schreibman, O'Neill, & Burke, 1983). Sources of such stress may include: the stigmatization associated with the disorder (Gray, 1993), difficulties in accepting the diagnosis (Harris, 1983), additional financial burdens (Holroyd & McArthur, 1976), loss of leisure time (Harris, 1983), fatigue associated with caring for the child (Sander & Morgan, 1997; Harris, 1983), and marital conflicts associated with rearing a child with developmental challenges (Harris, 1982; Holroyd & McArthur, 1976).

Like all families, families with autism must learn to deal with challenging life events (e.g., death, illness in the family) (Harris, 1994). Thus, it is imperative to “understand not only the specific sources of stress that these special needs families experience, but also how they cope with these demands, the factors that determine which families will respond more or less effectively to the stresses of their lives, and how their coping may impact the child’s development” (Harris 1994, p. 162).

Next, the manner in which individual family members view the child with autism may also have an impact on outcome (Schoeder & Le Blanc, 1996). For instance, Mathijssen, Koot, Verhulst, De Bruyn, and Oud (1998) investigated the correlation between family relationships and child psychopathology in a sample of 137 families referred to outpatient mental health services. Assessment of the relative association of the family dyads demonstrated that both the mother-child and the father-child relationship were related to child problem behaviors. Mother-child relationships were consistently more related to externalizing behaviors, while father-child relationships were particularly related to internalizing behavior. These results give support to the idea that more negatively qualified relationships are associated with problematic behavior. Conversely, positive parent-child relationships tend to be associated with less problem behavior.

Along with parent/child interactions, sibling relationships are affected in families with a developmentally challenged child (Rodrigue, Geffken, & Morgan, 1994). It has been argued that having a brother or sister with a handicap does not invariably lead to a troubled sibling relationship, but significant developmental challenges may arise (Harris, 1994). Such difficulties include: the frustration of dealing with an unresponsive brother or sister, the sacrifice of parental attention, discomfort caused by peer responses and disruption of family activities (Harris, 1983).

Although children with autism are seen as a source of stress to many parents, buffers may exist to assist a family in adapting to the special needs of their child. These include family cohesion, a good social support network, and effective coping skills (Harris, 1994). As such, an essential part of most intervention programs is to assist the parents in developing effective methods of coping with behavior problems (Howlin, 1989). According to Howlin (1989) "it is the long-term improvement in family functioning that is the ultimate goal, not simply the short term alleviation of specific behavioral difficulties." (p 210).

In summary, it is evident that family factors have the potential to impact prognosis in autism. However, much remains unknown. For instance, it is not clear which family factors are prognostically relevant to the syndrome of autism.

Purpose of the Current Study

The present study sought to examine the factors related to prognosis in children with autism. Prognostic factors were broadly grouped into the following categories: family variables (e.g., intact vs. divorced), the presence of specific behavioral disturbances, severity of autism at the time of diagnosis, age at the time of diagnosis, the presence of health-related conditions (e.g., presence of asthma) and disorders (e.g. mental retardation), gender, and the age at which specific developmental milestones were acquired (e.g., age of first word) (see Table 1 for a summary of

prognostic factors). Prognosis was measured by gains in cognitive abilities, social skills, language abilities, and reductions in autistic symptomatology. Gains in overall functioning (i.e. a combination of all four of these areas) were also considered.

Research Questions

The primary research question associated with the present study was: What factors are positively related to prognosis in children with autism? Prognosis was measured by gains in cognitive abilities, social skills, language abilities, reductions in autistic symptomatology, and overall functioning.

In order to address this question, it was necessary to examine which specific factors were related to outcome in the autistic sample. As such, the following secondary research questions were also considered:

1. Which family factors are most strongly associated with prognosis in autism?
2. Which behavioral disturbances, are most strongly associated with prognosis in autism?
3. Is severity of autism at the time of diagnosis associated with prognosis?
4. Is the age at which the child is diagnosed (i.e. before or after age three) associated with prognosis in autism?
5. Which health conditions/mental disorders are most strongly associated with prognosis in autism?
6. Is gender associated with prognosis in autism?
7. Is the age (i.e. in months) at which specific developmental milestones are achieved associated with prognosis in autism?

Table 1

Possible Factors Affecting Prognosis in Children with Autism

A. Family Variables

1. intact versus divorced family
2. birth order of the autistic child
3. number of siblings present
4. attachment behaviors such as difficulties with separation from the primary caregiver or incidence of attachment to inanimate objects
5. parental income

B. Behavioral Difficulties: Recurrent incidences of:

1. aggression towards self (Self injurious behaviors)
2. aggression towards others

C. Severity of Illness (Mild-Severe)

D. Age of Diagnosis (before or after age three)

E. Health related Conditions and Disorders: Presence or absence of:

1. asthma
 2. recurrent ear infections
 3. food allergies
 4. head injury
-

Table 1 (continued)

Possible Factors Affecting Prognosis in Children with Autism

5. difficulties at birth attributed by at least one of the following:
 - a. premature delivery
 - b. born in distress
 - c. breathing irregularities
 - d. jaundice
6. seizures/convulsions
7. mental retardation
8. other disorders

Retardation

F. Gender

G. Developmental Milestones (in months)

1. first crawl
 2. first word
 3. first sit
 4. first stand
 5. first steps
-

Chapter Three

Methodology

Sample

The age of participants at the time of the intake assessment at The Society for Treatment of Autism ranged from 32 months to 66 months ($M = 46.23$, $SD = 8.53$). At the time of the second or middle assessment ages ranged from 63-80 months ($M = 72.19$, $SD = 4.38$) and at the time of discharge the age of participants ranged from 51-72 months ($M = 59.84$, $SD = 6.24$). Not all children received middle or discharge assessments, which accounted for the age differences between each assessment period (i.e. children at middle assessment appear to be older than children at discharge assessment). Selection of participants was not random. That is, in order for children to be included in this study, participants had to have received at least two separate assessments. All participants received: 1) an intake, middle, and discharge assessment; 2) an intake and middle assessment; or 3) an intake and discharge assessment. All of the children included in this study had been formally diagnosed with a pervasive developmental disorder (PDD), specifically autism or PDD (Not Otherwise Specified) by a Chartered Psychologist, Psychiatrist, and/or Pediatrician. These two diagnostic categories were not differentiated in the current sample. It should be noted that children are referred to STA-EIP by a variety of sources. However, at the time of the study, the primary referral source was the Alberta Children's Hospital.

Description of Participating Agency

“The Society for Treatment of Autism is a registered charity striving for excellence in its treatment services to the autistic population, and related developmental disorders. The agency offers quality support, education and consultation services to families and the community and maintains that individuals be treated with dignity and respect. It employs a multidisciplinary team of professionals, which includes consulting psychiatrists, psychologists, speech pathologists, an occupational therapist, an assessment specialist, social workers, program coordinators, teacher/site coordinators, teaching assistants and early intervention therapists. In addition, a comprehensive range of services are offered to ensure effective therapy, training and care to those individuals with autism and other developmental disorders. Services include a residential treatment program, early intervention programs, adult services, foster care, family counselling and training, consultation, and community education” (Mission statement, Society for Treatment of Autism, 1996).

In terms of intervention, the treatment employed at STA-EIP is structured from a behavioral model. That is, the intervention program at STA-EIP follows behavioral principles (e.g. positive reinforcement). Each child’s treatment plan is individualized and geared to address the unique needs of the child. A low staff-child ratio is employed at STA-EIP, as many children receive behavioral services on a one-to-one basis.

Instruments

All data were extracted from existing client files. Some of the required information was obtained from a detailed application form, which asked parents for specific demographic information. The remaining information was gathered from formalized assessment reports. The standardized instruments from which data was extracted examined four specific areas: 1)

cognitive functioning, 2) adaptive functioning, 3) communication skills, and 4) autistic symptomatology. Moreover, the scores from these four areas were combined to explore overall functioning. The following section will outline the assessment instrument(s) utilized in each of the four areas of functioning (see Table 2).

Cognitive Functioning

Four different assessment tools were utilized to measure cognitive functioning in the present study: 1) The Bayley Scales of Infant Development – Second Edition (BSID II: Bayley, 1993), 2) The Arthur Adaptation of Leiter International Performance Scale (AALIPS: Arthur, 1949), 3) The Psychoeducational Profile - Revised (PEP-R: Schopler, Reichler, Bashford, Lansing, & Marcus, 1990), and 4) The Stanford-Binet Intelligence Scale: Fourth Edition (SB: FE; Thorndike, Hagen & Sattler, 1986a).

Bayley Scales of Infant Development. The Bayley Scales of Infant Development (BSID: II: Bayley, 1993) is a measure of infant development for children age two months to 42 months. It incorporates two standard scores obtained from a Mental Developmental Index and a Psychomotor Development Index. The Mental Developmental Index is obtained from a mental scale, which consists of 163 items. Items included in this scale involve sustained attention, shape discrimination, purposeful manipulation of objects, imitation and comprehension, problem solving, vocalization, memory, and naming objects. The Psychomotor Development Index, which is made up of the motor scale, contains 81 items that cover gross and fine motor abilities. Once the indexes are completed, a child is then given an age equivalent standard score. In terms of reliability, split reliability coefficients range from .81 to .93 on the mental scale and .68 to .92 on the motor scale. Although validity coefficients for children under 24 months are not reported,

Table 2

Psychometric Measures Utilized

A. Cognitive Ability

1. Bayley Scales of Infant Development, Second Edition (BSID II: Bayley, 1993).
2. Arthur Adaptation of Leiter International Performance Scale (AALIPS: Arthur, 1949).
3. Psychoeducational Profile - Revised (PEP-R: Schopler, Reichler, Bashford, Lansing, & Marcus, 1990).
4. Stanford-Binet Intelligence Scale: Fourth Edition (SB: FE; Thorndike, Hagen & Sattler, 1986a).

B. Adaptive Functioning

1. Vineland Adaptive Behavior Scale (VABS: Sparrow, Balla, & Cicchetti, 1984).

C. Communication Ability

1. Reynell Devale Language Scale (RDLS: Reynell, 1969).
2. Preschool Language Scale (PLS: Zimmerman, Steiner, & Pond, 1979).
3. Peabody Picture Vocabulary Test- Revised (PPVT-R: Dunn & Dunn, 1981).
4. Sequential Inventory of Communication Development-Revised (SICD-R: Hendrick, Prather, & Tobin, 1984).

D. Autistic Symptomatology

1. Childhood Autism Rating Scale (CARS: Schopler, Reichler, & Renner, 1988).
 2. The Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984).
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the Bayley reports a correlation of .57 between the Mental Development Index and the Psychomotor Development Index (Sattler, 1991).

Arthur Adaptation of Leiter International Performance Scale. The Arthur Adaptation of Leiter International (AALIPS: Arthur, 1949) is a nonverbal test of intelligence utilized in evaluating children age three to eight with sensory or motor deficits. Challenges in reading or verbal language are also assessed in the AALIPS. Fifty-four tests are arranged in an age-scale format. Children must arrange a series of blocks according to the appropriate symbols or pictures. Items range in difficulty from pairing of objects, shapes, and colors to items involving perceptual patterns, analogies, and concepts. Mental age is established from age-scale scores. An IQ can be obtained using the ratio method (i.e. $IQ = 100 \times MA/CA$). The AALIPS is reported to have satisfactory test-retest reliabilities, as well as adequate content, criterion-related and construct validity (Sattler, 1991).

Psychoeducational Profile. The Psychoeducational Profile - Revised (PEP-R: Schopler, Reichler, Bashford, Lansing, & Marcus, 1990) measures behavior and development in developmentally delayed children age six months to seven years. According to Schopler and Reichler (1979), it was designed to measure all characteristics of the autistic child that are not necessarily part of diagnosis. The PEP-R incorporates a developmental scale and a behavioral scale. The developmental scale assesses imitation, perception, fine and gross abilities, eye-hand coordination, cognitive performance and cognitive verbal ability. The behavioral scale examines the areas of relating, use of materials, sensory and language abilities. A developmental age is determined from the scores on the PEP-R. A strong correlation (i.e. .92) was revealed when determining inter-rater reliability. Validity is also reported to be satisfactory (Impara & Plake, 1998).

Stanford-Binet Intelligence Scale: Fourth Edition. The Stanford-Binet Intelligence Scale: Fourth Edition (SB: FE; Thorndike, Hagen & Sattler, 1986a) is a battery of 15 subtests which explore cognitive functioning in individuals age two to 23 years. It measures the areas of verbal reasoning, abstract/visual reasoning, quantitative reasoning, and short-term memory. The subtests of vocabulary, comprehension, absurdities, and verbal relations assess verbal reasoning. Abstract/Visual reasoning is determined by the subtests of pattern analysis, copying, matrices, and paper folding and cutting. Quantitative reasoning is assessed by the subtests of quantitative, number series, and equation building. Short-term memory is evaluated by the subtests of bead memory, memory for sentences, memory for digits, and memory for objects. Raw scores in the SB: FE are converted into three types of standard scores, subtest scores, area scores, and a composite score. The composite score is similar to the IQ scores employed in the Wechsler scales (Sattler, 1991). The SB: FE is reported to have excellent internal consistency and satisfactory content, criterion-related and construct validity (Sattler, 1991).

Adaptive Functioning

The Vineland Adaptive Behavior Scales: (VABS: Sparrow, Balla, & Cicchetti, 1984) were utilized to provide a measure of adaptive functioning. The VABS assesses the social competence of handicapped or nonhandicapped children from birth to 19 years of age. The Survey Form and the Classroom Edition of the VABS were used specifically in this study. Adaptive behavior is measured in the areas of communication, motor skills, daily living skills, and socialization. The communication domain assesses written, receptive, and expressive communication skills. The daily living skills domain examines domestic task performance, personal living habits, and behavior in the community. The socialization domain evaluates interactions with others. The motor skills domain assesses gross and fine motor coordination.

Parents are interviewed and scores are determined from the information gathered during the interview. Standard scores for each domain and an adaptive behavior composite are determined. Split-half, test-retest, and interrater reliability coefficients of the survey form are reported to be in the moderate to high range; validity has also been established (Sattler, 1991).

Communication Skills

The area of communication skills was measured by four tests of language ability: 1) Reynell Devale Language Scale (Reynell, 1969), 2) Preschool Language Scale (Zimmerman, Steiner, & Pond, 1979), 3) Peabody Picture Vocabulary Test- Revised (PPVT-R: Dunn & Dunn, 1981) and 4) Sequential Inventory of Communication Development-Revised (Hendrick, Prather, & Tobin, 1984).

Reynell Devale Language Scale. The Reynell Devale Language Scale (RDLS: Reynell, 1969) measures expressive language skills and verbal comprehension in children one to six years. It utilizes various stimuli (e.g., ball, spoon, and car) in a series of vignettes and test items correspond to the presentation of these vignettes. For this reason test items do not progress in order of increasing difficulty. It is recommended that all sections of the RDLS be administered to avoid underestimate a child's language ability (Conoley & Impara, 1985). Two scores are determined in the areas of verbal comprehension and expressive language. Internal consistency reliability coefficients for verbal comprehension and expressive language range from .80 to .90. Content validity is also reported to be satisfactory.

Preschool Language Scale. The Preschool Language Scale (PLS: Zimmerman, Steiner, & Pond, 1979) is reported to assess the receptive and expressive language ability of children from birth up to six years. More specifically, scores are derived in the subscales of auditory comprehension and expressive communication. Each subscale consists of 48 items and 12 age

levels. Within each age level, four items are administered. The span of age levels is six months except for the last two, which have a span of 12 months. The focus of the PLS is on four aspects of language: 1) language precursors (i.e. attention, vocal development, and social communication), 2) semantics (i.e. vocabulary, and concepts of quality, quantity, spatial and time sequence), 3) integrative thinking skills, and 4) structure (i.e. morphology and syntax). A total language score is then determined from these areas. Internal consistency is reported to range from .47 to .94 across age intervals and scales. The validity of the PLS is reported to be satisfactory (Conoley & Impara, 1985).

Peabody Picture Vocabulary Test- Revised. The Peabody Picture Vocabulary Test-Revised (PPVT-R: Dunn & Dunn, 1981) is a nonverbal, multiple choice test designed to measure the receptive knowledge, or hearing vocabulary of children ages two and a half through to adulthood. The test does not require reading ability, only that individuals have the ability to respond in some manner to yes or no items. The PPVT-R contains two forms. Each form consists of 175 plates, with each plate containing four pictures. Items are arranged according to increasing difficulty. Raw scores are converted to standard scores ($M = 100$, $SD = 15$). Split-half reliability coefficients for ages 2 years 6 months to 18 years ranges from .67 to .88 for Form L and .61 to .86 for Form M. Content validity is reported to be reasonably demonstrated in the PPVT-R and it has been found to moderately correlate with the Wechsler Intelligence Scale for Children- Revised (WISC-R) (Sattler, 1991).

Sequential Inventory of Communication Development-Revised. The Sequential Inventory of Communication Development-Revised (SICDR: Hendrick, Prather, & Tobin, 1984) assesses communication skills in the areas of receptive and expressive language in children four months to four years of age. That is, it examines receptive and expressive

processing and behavior. The receptive processing subtest items are categorized as semantic, syntactic, pragmatic, and perceptual. On the expressive processing subtest, items are classified as semantic, syntactic, pragmatic, and phonological. Receptive behavior is assessed by awareness, discrimination and understanding abilities, while expressive behavior is examined by imitation, initiating and responding behavior and verbal abilities (Smith, 1985). The SICDR is reported to have strong interrater and test-retest reliability. In terms of validity, content, construct and concurrent validity have been demonstrated (Smith, 1995).

Autistic Symptomatology

The Childhood Autism Rating Scale (CARS: Schopler, Reichler, & Renner, 1988) and The Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984) were utilized in the present study to assess autistic symptomatology. It should be noted that the E-2 was used for descriptive purposes only (i.e. to explore specific behavioral items). That is, scores from the E-2 were not utilized in the current study.

The Childhood Autism Rating Scale. The Childhood Autism Rating Scale (CARS: Schopler, Reichler, & Renner, 1988) evaluates 15 dimensions of behavior: relationships with people, imitation, affect, use of body, relation to non-human objects, adaptation to environmental change, visual responsiveness, auditory responsive ness, near receptive responsiveness, anxiety reaction, verbal communication, nonverbal communication, activity level, intellectual functioning and general impression. Children are observed in the presence of an adult and independently in play activities. Behaviors are then rated and a score is given for each of the dimensions. The general impression score, which is the total of each of the dimensions, falls under a continuum ranging from non-autistic to severe autism. The CARS is reported to have

high reliability, with a reliability coefficient of .94 and an interrater reliability of .74; it is also demonstrated to be a valid measure of rating autism (Schopler, Reichler, & Renner, 1988).

The Diagnostic Checklist for Behavior Disturbed Children, Form E-2. The Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984) is a questionnaire used to identify and classify children who display behaviors associated with autism. The E-2 is ideally completed by parents with children age three to five years (Foster and Lavoie, 1988). The E-2 evaluates the areas of motor development, physical disorders, responsiveness, social relations and language. According to Foster and Lavoie (1988), reliability of the E-2 remains unknown and validity is yet to be demonstrated. Attention will now turn to the variables which were examined during the course of this study.

Variables

The variables utilized in the present study were broadly categorized into two categories: predictor variables and outcome variables.

Predictor variables. Seven predictor variables in this study were examined: 1) family variables, 2) the presence of behavioral disturbances, 3) severity of autism at the time of diagnosis, 4) age at the time of diagnosis, 5) health-related conditions/disorders, 6) gender, and 7) the age of acquisition of specific developmental milestones (see Table 1). As for family variables, children were identified as coming from either an intact or divorced family. This was determined by examining the demographic information section of the data files. Information pertaining to birth order and number of siblings present in the family was also extracted from the demographic information section of each file. Furthermore, The Vineland Adaptive Behavior Scale: Classroom Edition (VABS: CE: Sparrow, Balla, & Cicchetti, 1984) was utilized to gather information regarding attachment. The Survey Form of the VABS (i.e. utilized for

measuring adaptive functioning) was not used in relation to attachment. To be more specific, four items from the Socialization Domain were utilized. These items were as follows: Attachment item A (i.e. child shows desire to please parent or caregiver), Attachment item B, (i.e. child labels happiness, sadness, fear and anger in self), Attachment item C (i.e. child addresses at least two familiar people by name), and Attachment item D (i.e. child laughs or smiles appropriately to positive statements).

The demographic information section of the data files also provided information pertaining to parental occupation and income. Once parental occupation was determined, the corresponding income for that particular occupation was taken from the Ministry of Supply and Services Canada (1996) 1993 tables of occupations and average incomes. In a single income family, only parental income was reported. In a dual income family, average incomes were combined to determine overall family income levels.

Behavioral difficulties were identified from The Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984). During the present study, specific items were selected to evaluate rigidity, recurrent incidences of aggression towards self (i.e. self-injurious behaviors) and aggression towards others. Rigidity was determined by examining scores taken from six questions from the E-2 (see Appendix D). A child was considered to be rigid if the parent endorsed three or more of the six specified items. Self-injurious behavior and aggression towards others were coded based on the parent's response to one item from the E-2 (see Appendix D). In addition, the presence of stimulatory behaviors was determined by examining certain sections of the assessment reports pertaining specifically to behavior. If stimulatory behaviors were discussed in these sections of the client files, presence of stimulatory behavior

was determined to be present. Children were then recorded as demonstrating stimulatory behaviors.

Another prognostic variable explored in the current study was severity of autism. Severity of autism was determined by examining the score the client obtained on the Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1988) at the time of intake. Scores on the CARS range from 15 to 60 (i.e. from non-autistic to severe autism).

The age of diagnosis was determined by examining available diagnostic reports. Children were identified as having been diagnosed before or after the age of three.

The presence of health-related conditions and disorders was also explored in relation to prognosis. Information pertaining to the occurrence of asthma, recurrent ear infections, food, allergies, seizures, head injury and mental disorders/conditions (not including mental retardation) was extracted from the demographic information section, diagnostic reports, and from the Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984). Difficulties at birth were also determined using these three sections of the data files. To be more specific, birth difficulties were operationally defined by presence of at least one of the following: premature delivery, born in distress, breathing irregularities, and jaundice. Mental retardation was determined by calculating a ratio IQ (i.e. mental age at the time of the first assessment divided by his/her chronological age multiplied by 100 (i.e. $IQ = MA / CA \times 100$). A child was identified as mentally retarded if his/her IQ fell below 70 (Sattler, 1991).

Further, gender and the age of acquisition of developmental milestones (i.e. first crawl, first word, first sit, first stand, and first steps) were coded from the background information section of the data file.

Outcome variables. In the present study, five different outcome variables were considered: gains in cognitive functioning, gains in adaptive functioning, gains in communication skills, reduction in autistic symptomatology, and gains in overall functioning (i.e. all four areas combined).

Mean ratios of monthly gains were calculated for each area of functioning and for overall functioning. That is, gains within each outcome variable were found by taking the difference between assessment scores at time one (intake) and time two (middle or discharge assessment) divided by the child's age (in months) at the time of the assessment. Time of assessment was calculated by determining the difference between the child's age at the second assessment minus the child's age at the first assessment. If a child received an intake and middle assessment only (i.e. no discharge assessment), the difference in scores was calculated using these two assessments.

Consent and Confidentiality

Consent was not needed directly from parents in this study. Upon admission to STA-EIP, parents are asked to sign a form, which grants permission for others to extract information from the archival data set for research purposes. However, in order to gain access to the files, it was necessary for the researcher to apply to STA-EIP for a position as a Research Volunteer. In order to be considered for such a position, an oath of confidentiality was signed, a police security clearance form was filled out, and a child welfare record check was completed. Once such personal information was gathered, the researcher was able to proceed with data collection (See Appendices B & C).

During the course of the study, the researcher was given access only to information pertinent to the present study, namely individual assessment and programming files. Also, data

were gathered in a manner which ensured anonymity. That is, individual subject names were not recorded. Rather, all subjects were assigned a number and this number was entered into the final data set once the required data was collected from the client's file. Once collected, the data were maintained in a file cabinet in the researcher's office. The researcher and her supervisors were the only individuals able to access the data set during the present study.

In the following section, the procedural steps involved in the current study will be outlined. A summary of the procedure is outlined in Table 3.

Procedure

The present study began with an exploration of prognostic factors. First, a survey of the existing empirical literature related to outcome was conducted in order to determine previously identified prognostic factors related to autism. Once this exploration was completed, an examination of the data available at STA-EIP took place. Three data files were examined to allow the researcher to familiarize herself with the information contained in each file (i.e., which could be gathered for use in the current study). Third, after the data files were examined and exploration of these files was completed, it was determined that certain prognostic factors would be examined. Fourth, given the information gathered from both the empirical literature and the available information in the STA-EIP data files, the researcher derived a list of potential prognostic factors (see Table 1). This list was created with the assistance of the researcher's supervisor and co-supervisor. It is important to note that the files of some subjects were incomplete. As such, some of the subjects were eliminated from the study.

Fifth, data were gathered by extracting information from the files of the 39 children who met the inclusion criteria for this study (i.e. two or more assessments). As previously noted, each file included a parental consent form, family and child background, medical and diagnostic

history, and the results of the standardized assessments which were completed during the child's tenure at STA-EIP. During the extraction of data, each file was examined individually and the required information was gathered. Data pertaining to the outcome variables (e.g. cognitive functioning), had been previously coded by other Researcher Volunteers at STA-EIP.

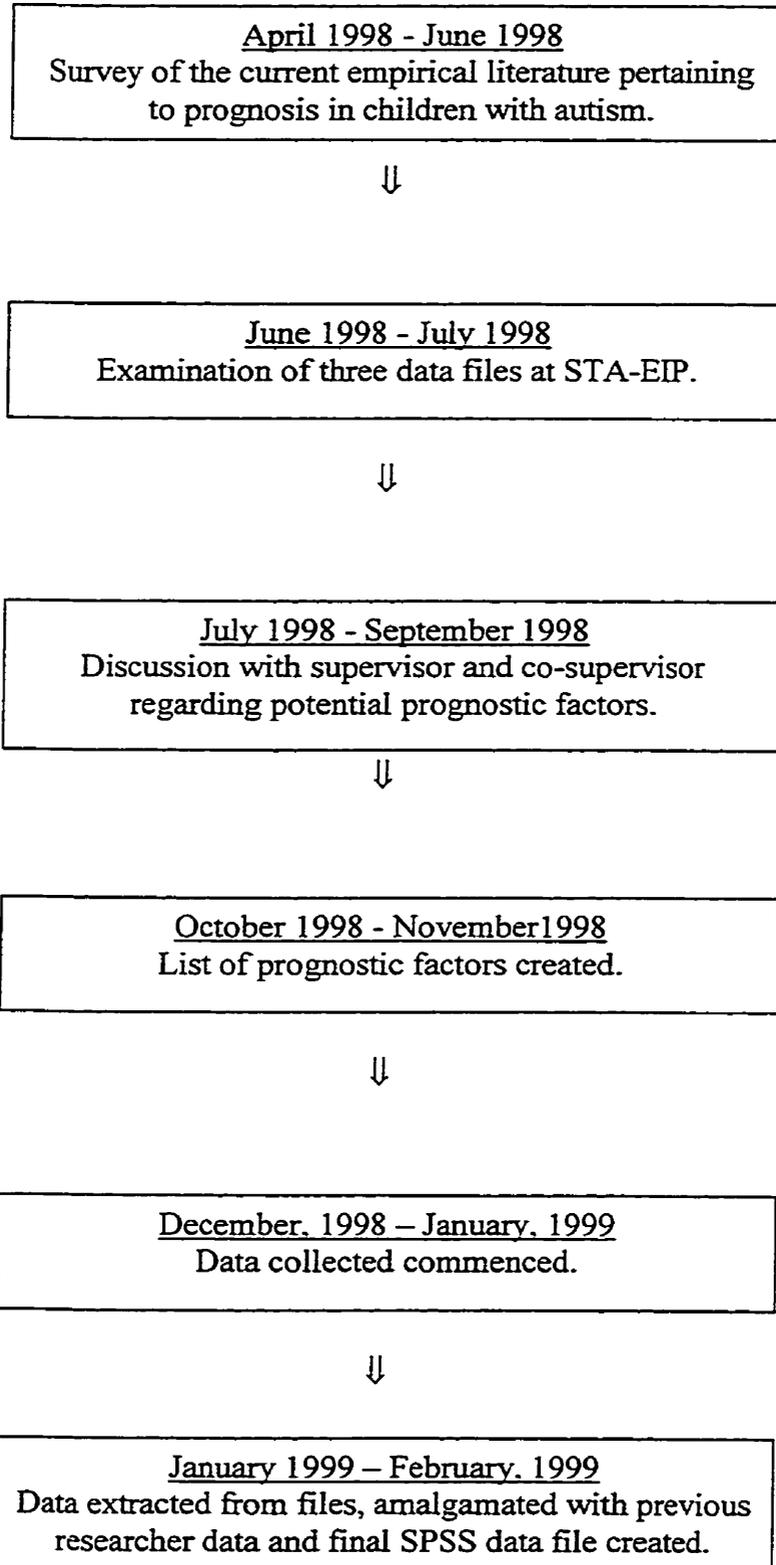
Finally, once all of the data were collected, information was coded onto an SPSS data file. The files containing the outcome data (i.e. information gathered by other researchers) were amalgamated with the current researcher's SPSS data file. A final SPSS data file was then created. Data collection took approximately one and a half months to complete.

Statistical Analyses

Considering the exploratory nature of the present study, descriptive statistics, correlational analyses, t-tests, and regression analyses were performed to examine prognostic factors in children with autism. The statistical package SPSS was utilized for all data analyses in this study.

Table 3

Monthly Time Line of Procedure



Chapter Four

Results

Demographic Information

The files of thirty-nine children between the ages of two and eight were reviewed during the course of the study. All of the participants had been formally diagnosed with a Pervasive Developmental Disorder (PDD), specifically Autistic Disorder or PDD (Not Otherwise Specified). Demographic information was collected at the time of intake. In regards to family variables, 79.5 % of participants came from intact families, with a range from 0-3 siblings per family. In regards to birth order, 26% of participants were reported to be the eldest child in the family, while 67% were indicated to be the youngest. Only one participant was reported to be an only child. The reported income levels for parents of participants are reported in Table 4. These income levels were determined from the Ministry of Supply and Services Canada (1996) 1993 tables of average incomes. In a dual income family, average incomes were combined to determine income levels. In addition, parental occupation is outlined in Table 5.

In terms of behavioral difficulties, 20 children were reported to be aggressive towards others while 19 were reported to be aggressive towards self. Severity of autism, as measured by the CARS ranged from non-autistic to severe in these participants. Twenty-one children were reported to be in the mild-moderate range, while 14 were indicated to be severe. The other four children fell into the non-autistic range of the CARS. In terms of diagnosis, 20 children were reported to have been diagnosed before the age of three. In relation to health, 21 children were indicated to have at least one health-related concern in addition to autism or PDD (see Table 6).

Table 4

Summary of Parental Income Levels

Income Level	Frequency	Percentage
1. 10,000 – 20,000	0	0
2. 21,000 – 30,000	3	9.1
3. 31,000 – 40,000	12	36.4
4. 41,000 – 50,000	4	12.1
5. 51,000 – 60,000	5	15.2
6. 61,000 – 70,000	5	15.2
7. 71,000 – 80,000	3	9.1
8. 81,000 and up	1	3

*Based from 31 families

**If a dual income family, incomes combined.

Table 5

Classifications of Parental Occupation

Occupation	Percentage
1. Entrepreneurial	7.7
2. Professional/Management	41
3. Skilled Labor	27.8
4. Other	19.4

Table 6

Frequency of Comorbid Health-Related Conditions And Disorders

Condition or Disorder	Number of Children Affected
1. Recurrent Ear Infection	17
2. Allergies	8
3. Epilepsy	5
4. Failure to Thrive	5
5. Asthma	3
6. Pica	1
7. Tuberous Sclerosis	1
8. Cerebral Palsy	1
9. Lung Disease	1
10. Gastrointestinal Reflux	1
11. Fragile X	1
12. Attention Deficit Disorder	1
13. Developmental Language Disorder	1

Twelve participants had at least one comorbid condition/disorder, while seven participants had two conditions/disorders, one had three conditions/disorders and one had four conditions/disorders. In addition, 77% of the participants also met diagnostic criteria for mental retardation.

In addition, thirty-six percent of participants' mothers reported problems during pregnancy. Fifty-seven percent of participants' mothers reported a natural delivery, while 27% indicated a caesarian birth, two percent a breech delivery, and five percent reported the use of forceps. Thirty-seven percent of participants' mothers reported health problems at birth (e.g., jaundice, fever, and blue body).

In relation to gender, thirty-one males and eight females participated in this study. In terms of developmental milestones, the ages at which developmental milestones were acquired is presented in Table 7. In comparison to developmental norms (Berns, 1994), all milestones except for the age of first word were reported to be in the average normative age range. Developmental norms were determined from charts of physical, motor and language development (Berns, 1994).

Correlational Analyses

Pearson correlation coefficients, contingency coefficients and Spearman correlation coefficients were calculated in order to determine the relationship among the predictor variables which were theorized to measure attachment. The selection of statistical procedures was made on the basis of the type of data being included in the analysis.

Attachment items were taken from the Socialization Domain (i.e. Interpersonal Relationships subdomain) of the Vineland Adaptive Behavior Scales: Classroom Edition.

Table 7

Average Age of Acquisition of Developmental Milestones

Milestone	<u>M</u>	<u>SD</u>	Range	Minimum-Maximum
1. Crawling	10.1	4.46	15.5	7 – 22.5
2. First Word	17.2	7.07	23	9 – 32
3. Sitting Alone	8.1	3.55	14	4 – 18
4. Standing	11.3	3.57	15	5 – 20
5. First Steps	14.6	5.74	28	9 – 37

*Reported in months

All mean developmental milestones were reported to be in the normative range, **EXCEPT for the age of first word (Berns, 1994).

(Sparrow, Balla, & Cicchetti, 1984). Attachment item A (i.e. shows desire to please parent or caregiver), was found to be significantly positively correlated with Attachment item C (i.e. addresses at least two familiar people by name), $r = .61$, $p < .01$ and Attachment item D (i.e. laughs or smiles appropriately to positive statements), $r = .37$, $p < .05$. Attachment item B (i.e. labels happiness, sadness, fear and anger in self) was significantly positively correlated with Attachment item D, $r = .52$, $p < .01$.

Contingency Coefficients were calculated to determine the degree of association between attachment items and other predictor variables. All Attachment items were found to be associated with mental retardation (MR), Attachment item A and MR, $C = .45$, $p < .01$, Attachment item B and MR, $C = .35$, $p < .05$. Attachment item C and MR, $C = .46$, $p < .01$, and Attachment item D, $C = .52$, $p < .002$. Such results indicate that children identified as mentally retarded were rated by teachers as displaying significantly less attachment behavior. The presence of self stimulatory behaviors was also found to be associated with Attachment A, $C = .516$, $p < .002$. Children with self stimulatory behaviors appeared to demonstrate less attachment behavior.

Spearman correlation coefficients were also utilized to explore the relationship between attachment and severity of autism. It was found that severity was negatively correlated with Attachment item A, $r = -.35$, $p < .05$, and Attachment item C, $r = -.45$, $p < .01$. To be more specific, as severity increased, attachment behavior tended to decrease. It appears that children with more severity demonstrated less desire to please and address a familiar other. See Table 8 for a summary of the relationships amongst the attachment variables.

Other significant correlation coefficients were also found when the relationship among predictor variables was explored. Utilizing a Spearman correlation, mental retardation was

Table 8

Relationships Among the Attachment Variables

Variables	Statistic
Pearson Correlation	
1. Attachment A and:	
a) Attachment C	.61**
b) Attachment D	.37*
2. Attachment B and Attachment D	
	.52**
Contingency Coefficients	
3. Mental Retardation and:	
a) Attachment A	.45**
b) Attachment B	.35*
c) Attachment C	.46**
d) Attachment D	.52**
4. Stimulatory Behaviors and:	
a) Attachment A	.52**
Spearman Correlation Coefficients	
5. Severity and:	
a) Attachment A	- .35*
b) Attachment C	- .45**

*p < .05

**p < .01

found to be positively correlated with severity, $r = .50$, $p < .00$. Not surprisingly, children who presented with mental retardation were also reported to be more severe.

T-Test Analyses

A number of t-tests were performed in order to determine if significant differences existed between groups of specific predictors variables and the dependent variables (i.e. mean ratio of monthly gains). To be more specific, five dependent variables were examined (i.e. cognitive functioning, adaptive functioning, communication skills, autistic symptomatology, and overall functioning). The mean ratio of monthly gains was determined for each dependent variable by taking the difference between assessment scores at time one (intake) and time two (middle or discharge assessment) divided by the child's age (in months) at the time of the assessment. Time of assessment was calculated by determining the difference between the child's age at the second assessment (i.e. at discharge) minus the child's age at the first assessment (i.e. second assessment score – first assessment score ÷ second assessment age – first assessment age). If a child had received an intake and middle assessment only (i.e. not discharge assessment), the difference in scores was calculated from intake to middle assessment. The differences in ages across children at the time of each assessment was accounted for by such a calculation. For all dependent variables except symptomatology, positive change was represented by increases in the mean ratio of monthly gains. As for symptomatology, positive change was demonstrated by decreases (i.e. reductions in autistic behaviors). Overall functioning was calculated by computing the mean of the areas of functioning combined (i.e. cognitive functioning, adaptive functioning, communication skills, and autistic symptomatology) at discharge minus the mean of the areas of functioning at intake divided by the age at discharge minus the age at intake (i.e. mean discharge score – mean intake score ÷ discharge age - intake

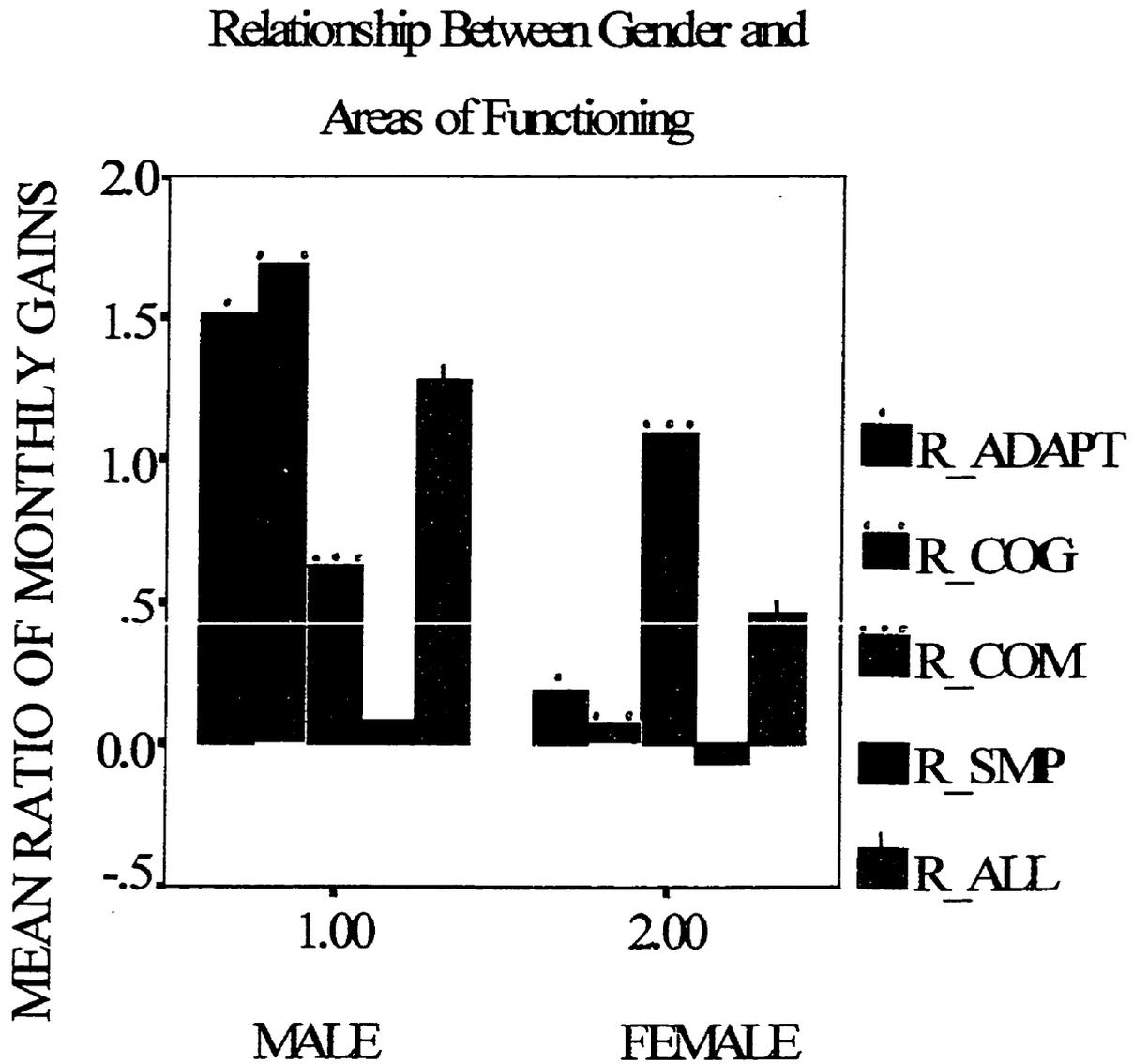
age). For autistic symptomatology, mean scores were reversed at intake and discharge), in order that overall gains be measured by increases, not decreases in mean monthly ratios of change (i.e. instead of mean discharge score – mean intake score, this calculation utilized mean intake score – mean discharge score for autistic symptomatology).

Levene's Test for Equality of Variances was also performed to determine if equality of variances could be assumed. Significant differences existed between males and females in the area of adaptive functioning $t = 2.325$, $df = 34$, $p < .05$. That is, males demonstrated a significantly higher monthly rate of change than females (see figure 1). Moreover, rigidity was found to differentiate children in the area of communication. Items selected from The Diagnostic Checklist for Behavior Disturbed Children, Form E-2 (Rimland, 1984) were used to assess rigidity. Differences between children in terms of rigidity was also discovered to be statistically significant in communication, $t = 2.365$, $df = 25$, $p < .05$. Children who did not meet the criteria for rigidity had higher mean ratios of monthly change in communication than those children reported to demonstrate rigidity. It was also found that differences emerged between autistic children who had also been diagnosed with or without mental retardation and children with or without epilepsy. However, such differences were not found to be statistically significant (For a summary of significant t-tests, see Table 9).

Univariate Regression Analyses

Univariate analyses were performed to investigate the relationship between each prognostic variable and the aforementioned areas of functioning (i.e. cognitive functioning, adaptive functioning, communication skills, autistic symptomatology, and overall functioning). As for family variables, Attachment item C, the ability to address a familiar other, was related to gains in cognitive ability, $F(1, 30) = 4.59$, $p < .05$, Adjusted $R^2 = .10$, adaptive functioning, $F(1,$

Figure 1



*please note a **negative** mean ratio in **R_SMP ONLY** indicates a positive mean monthly change.

Legend

R_Adapt = Adaptive Functioning

R_Cog = Cognitive Functioning

R_Com = Communication Skills

R_Smp = Autistic Symptomatology

R_All = Overall Functioning

Table 9

Summary of Significant T-tests

Variables	Mean	Area	T-Test
1. Sex:			
Females	.36		
Males	.68		
			Adaptive functioning $\underline{t} = 2.325, df = 34, p < .05.$
2. Rigidity			
Not Rigid	.83		
Rigid	.01		
		Communication	$\underline{t} = 2.365, df = 25, p < .05.$

31) = 6.49, $p < .05$, Adjusted $R^2 = .15$, and overall functioning, $F(1, 31) = 9.67$, $p < .00$, Adjusted $R^2 = .21$. Children who were reported to be able to address familiar others were found to have higher mean monthly ratios of change in these three areas of functioning. Moreover, family composition (i.e. intact versus divorced) was found to be related to gains within the domain of communication skills, $F(1, 25) = 4.91$, $p < .05$, Adjusted $R^2 = .13$. Children from divorced families demonstrated lower mean monthly ratios of change in the communication area than children from intact homes. In terms of comorbid mental conditions/disorders, mental retardation was found to be related to changes in adaptive functioning, $F(1, 35) = 6.08$, $p < .05$, Adjusted $R^2 = .12$. Children who were mentally retarded demonstrated lower mean monthly ratios of change in the area of adaptive functioning, than those without such comorbidity. In relation to behavioral disturbances, rigidity was found to be related to gains within the domain of communication skills, $F(1, 25) = 5.59$, $p < .05$, Adjusted $R^2 = .15$. Children who did not display rigidity demonstrated higher mean monthly ratios of change in the area of communication skills than children presenting with rigid behaviors. Finally, severity of autism was found to be related to gains in adaptive functioning, $F(1, 36) = 9.10$, $p < .01$, Adjusted $R^2 = .18$. Children who scored higher on the CARS were demonstrated to have lower mean monthly ratios of change in adaptive functioning (for a summary of univariate analyses, see Table 10).

Multiple Regression Analyses

Step-wise multiple regression analyses were performed to determine which family variables, behavioral disturbances, comorbid mental conditions/ disorders and developmental milestones were most strongly associated with prognosis. These analyses employed the ratio of monthly change in each area of functioning as previously described. In terms of family variables, the predictor intact/divorced was found to be significantly related to gains within the

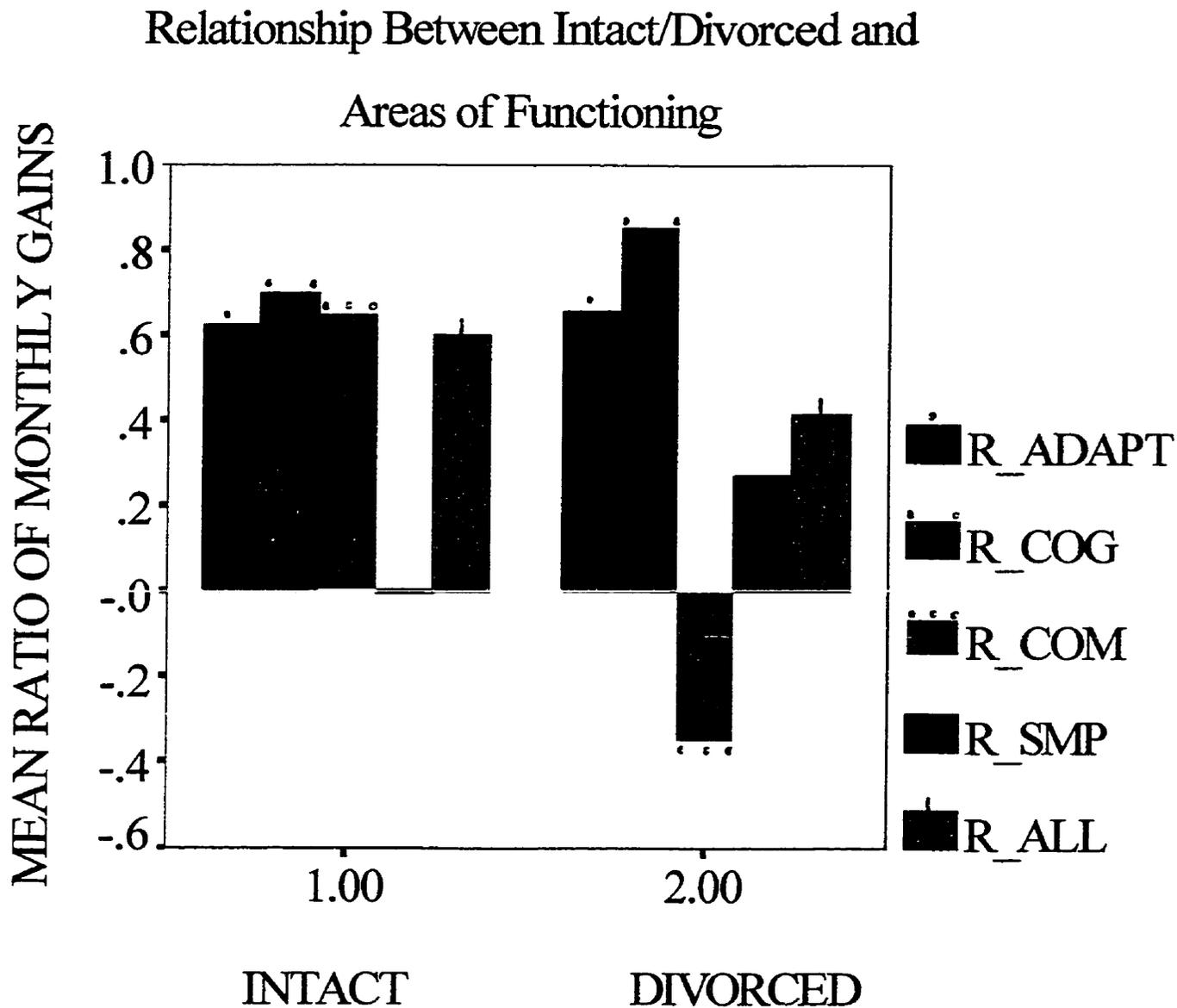
Table 10

Summary of Significant Univariate Regression Analyses

Predictor Variable	Area	F Value
1. Attachment C	Cognitive functioning	$F(1, 30) = 4.59, p < .05, \text{Adjusted } R^2 = .10.$
2. Attachment C	Adaptive functioning	$F(1, 31) = 6.49, p < .05, \text{Adjusted } R^2 = .15.$
3. Attachment C	Overall functioning	$F(1, 31) = 9.67, p < .00, \text{Adjusted } R^2 = .21.$
4. Intact/divorced	Communication skills	$F(1, 25) = 4.91, p < .05, \text{Adjusted } R^2 = .13.$
5. Mental Retardation	Adaptive functioning	$F(1, 35) = 6.08, p < .05, \text{Adjusted } R^2 = .12.$
6. Rigidity	Communication skills	$F(1, 25) = 5.59, p < .05, \text{Adjusted } R^2 = .15.$
7. Severity of autism	Adaptive functioning	$F(1, 36) = 9.10, p < .01, \text{Adjusted } R^2 = .18.$

domain of communication, $F(1,23) = 7.3, p < .05, \text{Adjusted } R^2 = .21$ (see figure 2). Children from divorced families demonstrated poorer monthly ratios of change in the area of communication. As for behavioral disturbances, rigidity was found to be significantly related to communication skills, $F(1,25) = 5.59, p < .05, \text{Adjusted } R^2 = .183$ (see figure 3). That is, children who do not display rigidity tended to evidence greater gains in the communication domain. Although not found to be significant, the absence of aggression towards others and self stimulatory behaviors were associated with gains in all areas (see figures 4 and 5 respectively). In the domain of health-related conditions and/or disorders, no predictor variables, other than mental retardation, were discovered to be significantly related to the ratio of monthly change. Mental retardation was found to be significantly related to adaptive functioning, $F(1,18) = 5.625, p < .05, \text{Adjusted } R^2 = .196$, cognitive functioning, $F(1,17) = 6.659, p < .05, \text{Adjusted } R^2 = .239$, communication, $F(1,13) = 8.42, p < .012, \text{Adjusted } R^2 = .346$ and overall functioning, $F(1,18) = 17.085, p < .01, \text{Adjusted } R^2 = .458$. Children without mental retardation demonstrated higher ratios of monthly change than those children with mental retardation (see figure 6). In terms of developmental milestones, age of a child's first word was demonstrated to be significantly linked to gains in overall functioning, $F(2,18) = 5.81, p < .01, \text{Adjusted } R^2 = .325$. Children with a first word before the age of one demonstrated higher mean ratios of overall monthly change than children than those who spoke after age one. (For a summary of multiple regression analyses significant results, see Table 11).

Figure 2



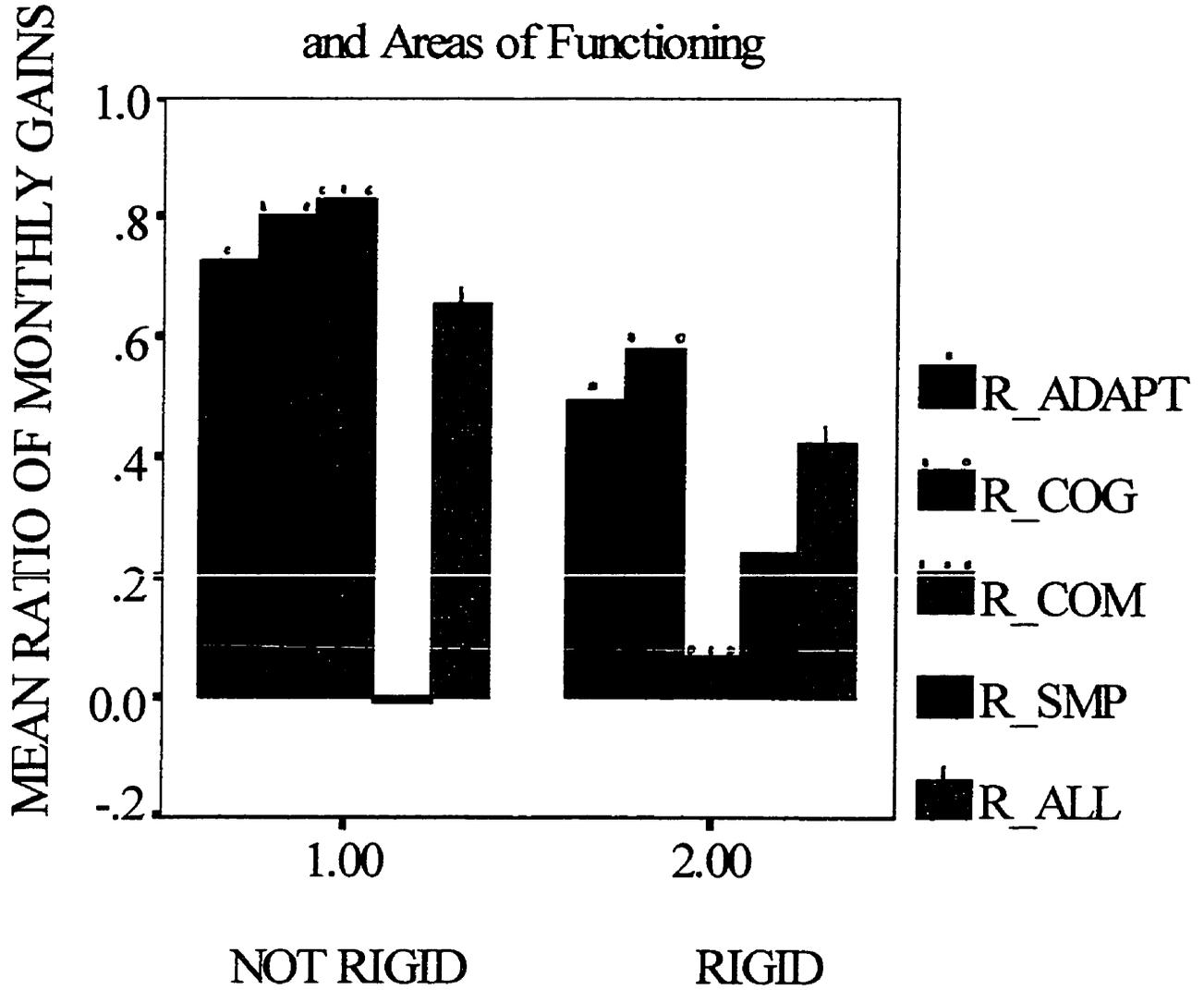
*please note a **negative** mean ratio in **R_SMP ONLY** indicates a positive mean monthly change.

Legend

R_Adapt = Adaptive Functioning
 R_Cog = Cognitive Functioning
 R_Com = Communication Skills
 R_Smp = Autistic Symptomatology
 R_All = Overall Functioning

Figure 3

Relationship Between Rigidity
and Areas of Functioning

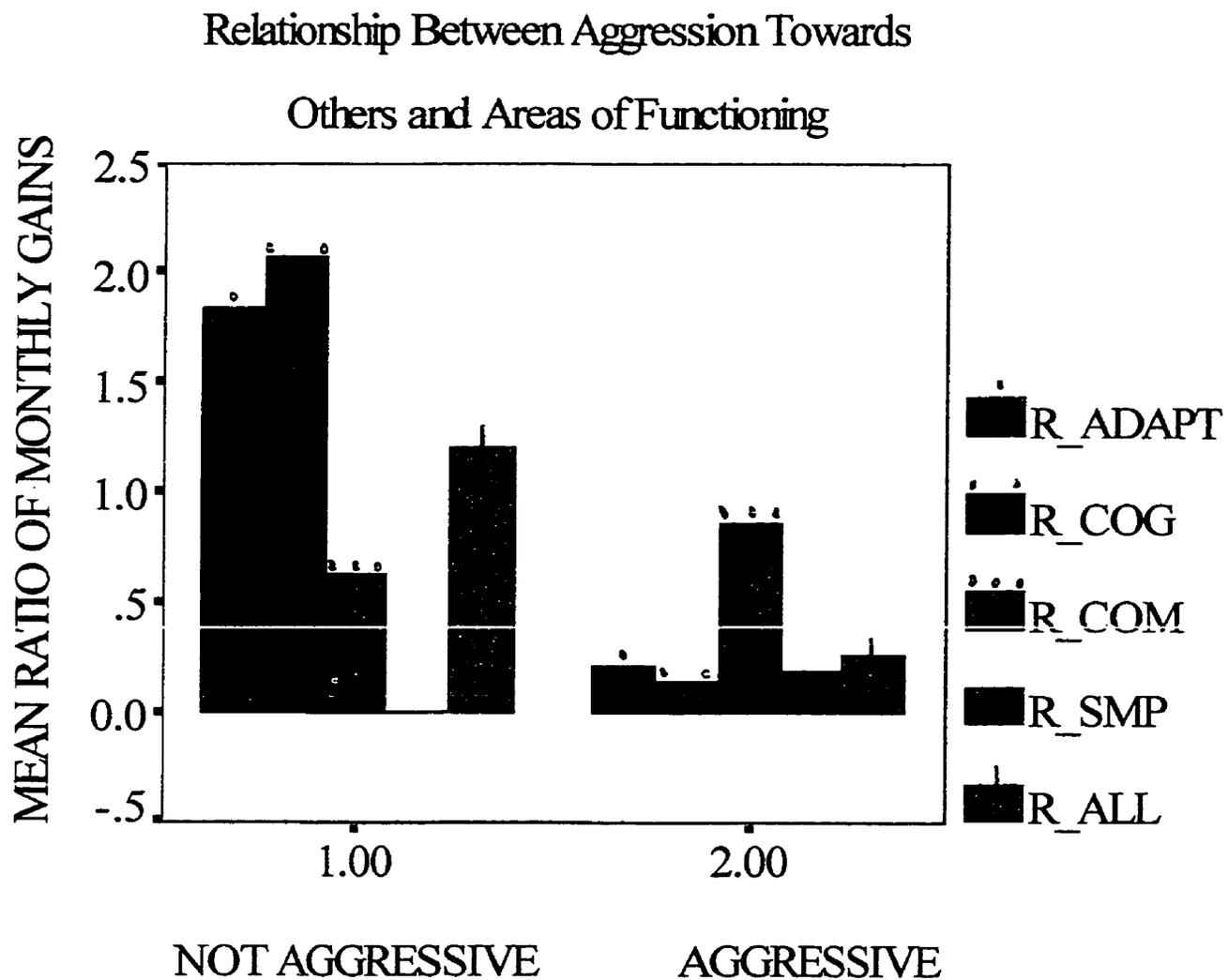


*please note a **negative** mean ratio in **R_SMP ONLY** indicates a positive mean monthly change.

Legend

- R_Adapt = Adaptive Functioning
- R_Cog = Cognitive Functioning
- R_Com = Communication Skills
- R_Smp = Autistic Symptomatology
- R_All = Overall Functioning

Figure 4



*please note a **negative** mean ratio in **R_SMP ONLY** indicates a positive mean monthly change.

Legend

R_Adapt = Adaptive Functioning

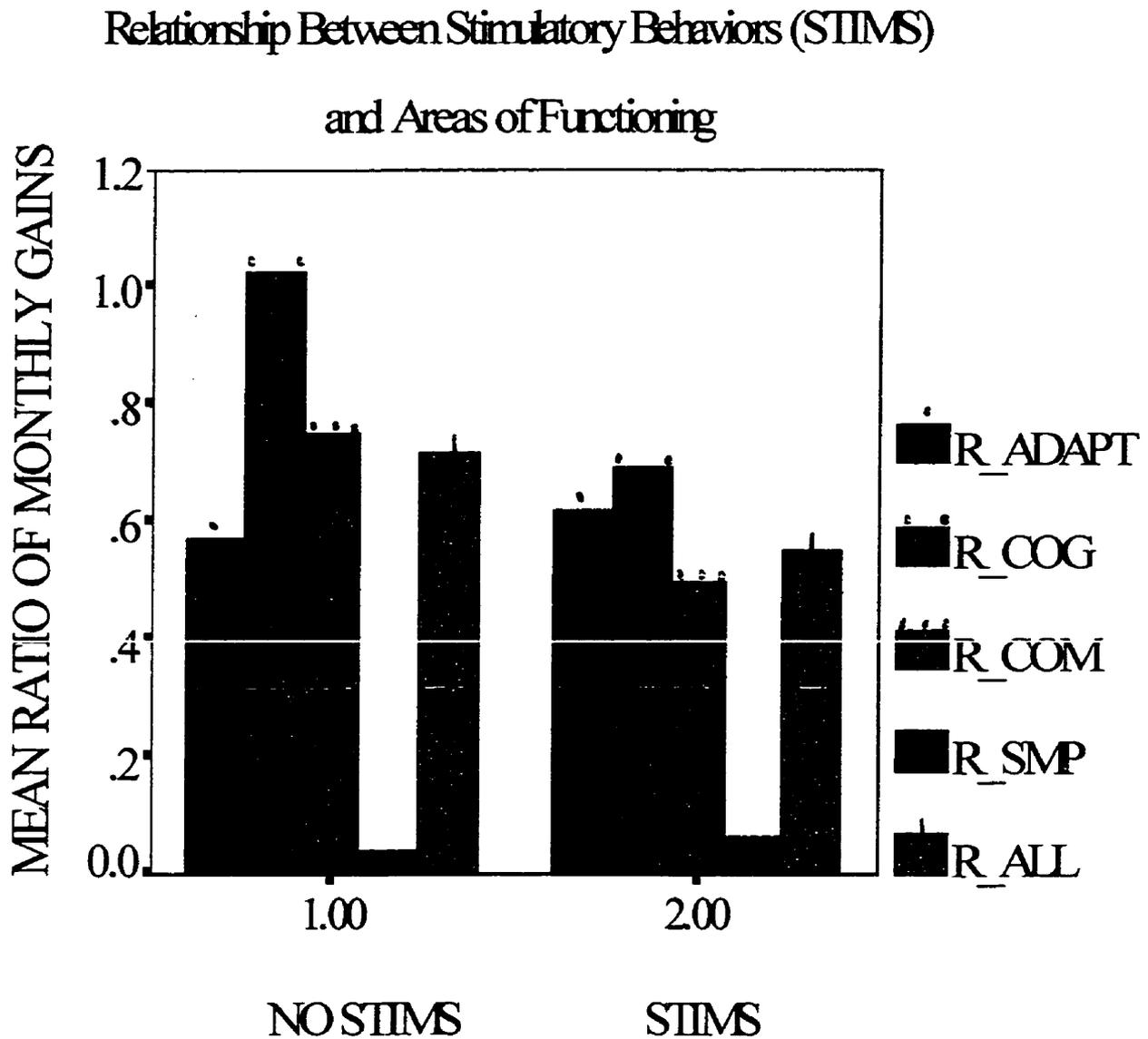
R_Cog = Cognitive Functioning

R_Com = Communication Skills

R_Smp = Autistic Symptomatology

R_All = Overall Functioning

Figure 5

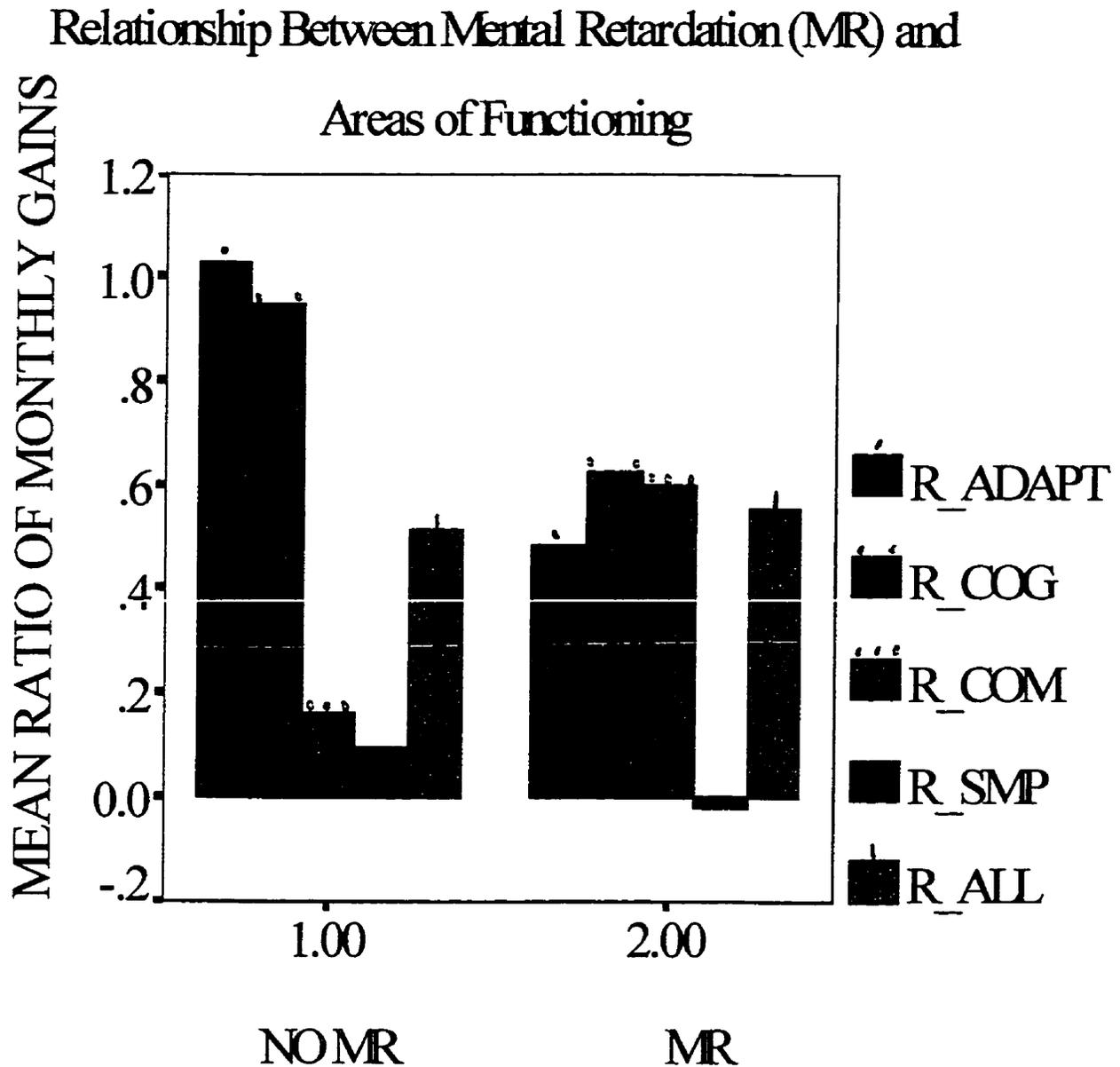


*please note a **negative mean ratio in R_SMP ONLY** indicates a positive mean monthly change.

Legend

R_Adapt = Adaptive Functioning
 R_Cog = Cognitive Functioning
 R_Com = Communication Skills
 R_Smp = Autistic Symptomatology
 R_All = Overall Functioning

Figure 6



*please note a **negative** mean ratio in **R_SMP ONLY** indicates a positive mean monthly change.

Legend

R_Adapt = Adaptive Functioning
 R_Cog = Cognitive Functioning
 R_Com = Communication Skills
 R_Smp = Autistic Symptomatology
 R_All = Overall Functioning

Table 11

Summary of Significant Multiple Regression Analyses

Predictor Variable	Area	F Value
1. Intact/divorced	Communication skills	$F(1,21) = 4.64, p < .05, \text{Adjusted } R^2 = .142.$
2. Rigidity	Communication skills	$F(1,25) = 5.59, p < .05, \text{Adjusted } R^2 = .183.$
3. Mental retardation	Adaptive functioning	$F(1,18) = 5.63, p < .05, \text{Adjusted } R^2 = .196.$
4. Mental retardation	Cognitive functioning	$F(1,17) = 6.66, p < .05, \text{Adjusted } R^2 = .239.$
5. Mental retardation	Communication	$F(1,13) = 8.42, p < .01, \text{Adjusted } R^2 = .346.$
6. Mental retardation	Overall functioning	$F(1,18) = 17.09, p < .01, \text{Adjusted } R^2 = .458.$
7. Age of First Word	Overall functioning	$F(2,18) = 5.81, p < .01, \text{Adjusted } R^2 = .325.$

It is important to note that, although statistical significance was established in these analyses, the clinical relevance of such significance will vary, depending on the amount of variance accounted for in each of the aforementioned results. For instance, in regards to mental retardation and cognitive functioning, MR accounted for 24% of the variance, while in terms of communication, rigidity only accounted for 18% of the variance.

Chapter Five

Discussion

The purpose of this study was to gain information about the factors related to prognosis in children with autism (i.e. family variables, presence of specific behavioral disturbances, severity of disorder, the age at time of diagnosis, presence of specific medical conditions and disorders, gender, and the acquisition of developmental milestones). Gains or decreases in the areas of cognitive functioning, adaptive functioning, communication, autistic symptomatology, and overall functioning (i.e. all four areas combined) were utilized to measure prognosis. In order to examine which factors significantly impacted prognostic outcome, seven research questions were specifically examined. These research questions examined in the present study were as follows: 1) Which family factors are most strongly associated with prognosis in autism? 2) Which behavioral disturbances are most strongly associated with prognosis in autism? 3) Is severity of autism associated with prognosis? 4) Is the age at which the child is diagnosed associated with prognosis in autism? 5) Which health conditions/mental disorders are most strongly associated with prognosis in autism? 6) Is gender associated with prognosis in autism? and 7) Is the age at which specific developmental milestones are achieved related to prognosis in autism? The following sections will address the findings associated with each research question and the potential implications of each of the obtained results.

Research Question One

Research Question one explored family variables (e.g., intact or divorced family). It was demonstrated that such composition was significantly related to the participants' mean monthly gains in communication skills. However, other areas of functioning were not found to be

significantly different between children from intact versus divorced families. Children from divorced families demonstrated negative mean monthly ratios of change in the area of communication. There are at least four possible explanations for this finding. First, it may be that the stressor of parental divorce impacted or even impeded the development and/or use of communication skills. According to Wolchik et al. (1985), divorce is likely to be a stressful experience for children; as it is associated with interpersonal hostility. A meta-analysis conducted by Amato and Keith (1991) also concluded that parental conflict during separation and /or divorce can have a negative impact on children. For instance, such conflict may lead parents to interact less effectively with their children (Hetherington, Cox, & Cox, 1982; Wallerstein & Kelly, 1980).

Second, it is plausible to suppose that parental divorce may have had a negative impact on the frequency and/or quality of social-communicative interactions in the family. It is possible that children feel unable to respond to others during family conflict, or perhaps prefer to isolate themselves from such hostility, which in turn would reduce the amount of communicative contact. Parents may also limit their interactions with the autistic child due to the chronic stress associated with the marital conflict.

Third, it may also be the case that divorcing families, as well as single parent families, have less time to address their children's needs. For instance, divorcing and/or single parent families may have less time to attend parent training/education sessions, to follow through with treatment recommendations, or to arrange and transport the child to therapeutic programs (e.g. speech therapy sessions).

Finally, caring for an autistic child with poorer communication skills may have perpetuated the likelihood of divorce in this sample. Families in this study may have divorced

prior to the time the demographic form and initial assessment were completed. Moreover, children challenged with limited communication may have been a particular stressor for parents. Harris (1994) delineates that children with autism are seen as a source of stress to many parents. It has also been proposed that such stress ultimately affects the family as a whole (Harris, 1992). Therefore, it is fair to postulate that it may also contributed to the divorce event. This can be supported by Holroyd and McArthur (1976) who demonstrated that marital conflicts were often associated with rearing a child with developmental challenges. Rodrigue et al. (1990) also found that mothers of children with autism reported less marital satisfaction than mothers of Down syndrome children and developmentally normal children. According to Harris (1983), “the needs and demand of the autistic child are a source of chronic stress, which can spill over into the marital relationship. The presence of the child may take the joy out of life and leave a couple with little reserve of good feeling to bring to the marriage” (p 87).

Since children from divorced families evidence less progress with regards to their communication skills, it is important to consider the implication for intervention programs. That is, treatment professionals should consider ways to buffer the autistic child from the potential impact of divorce. They should also consider the unique needs of single parent families. For instance, programs could assist families in maintaining structure in the home during the divorce and provide assistance to ensure treatment recommendations are followed.

Cutler and Kozloff (1987) delineated that parents of children with autism require specific support services to enhance their children’s treatment. According to Cutler and Kozloff (1987), the following services are necessary: 1) adequate education for children year round, provided by individuals with sufficient knowledge of autism; 2) respite care in order that parents may have planned relief from the daily responsibilities of caring for their child; 3) home training skills so

that parents can become more effective in assisting and teaching their child; 4) basic advocacy skills in order that they may have the knowledge and understanding necessary to effectively access services and financial support; and 5) an array of social supports such as peer groups and counseling services.

In addition, given the stressors associated with having an autistic child in the family, it may be helpful for professionals to explore the possible benefits of incorporating a family systems approach into the overall treatment plan. Such a component to intervention could assist the family in dealing with the impact of living with an autistic child (Harris, 1982). For instance, coupled with a individual treatment program for the child, a systems approach could facilitate the development of tools and strategies for the family to utilize when dealing with the stressors of associated with having an autistic family member (Harris, 1982).

Although not determined to be statistically significant, the findings pertaining to birth order are worthy of mention. Sixty-seven percent of the children in this study were identified as being the youngest sibling in the family. Perhaps it was the case that the stress associated with caring for their child with autism made parents reluctant to have subsequent children. Given that the incidence of autism is 50 times higher among siblings (i.e. 2 out of 100; Baron-Cohen, 1995; (Popper & Steingard, 1996; Smalley, Asarnow, & Spence, 1988) than in the general population (i.e. 1 out of 1000; Volkmar et al., 1997), it seems reasonable that parents may choose not to have another child, for fear that the subsequent child may also be diagnosed with autism.

Research Question one also examined whether attachment was associated with prognosis in autism. In this study, Attachment item C, the ability to address at least two familiar people by name, was positively associated with prognosis, as children with this ability demonstrated significantly higher mean monthly gains in the areas of cognitive functioning, adaptive

functioning, and overall functioning (i.e. cognitive functioning, adaptive functioning, communication skills and autistic symptomatology). One reason for such a finding may be that the ability to show differential responses to certain individuals is one of the core building blocks for the development of social relations. More specifically, the establishment of such an important developmental marker could, in turn, significantly impact functioning, given that overlap exists across development. That is, the development of social relationships are believed to affect the development of language, cognition, and behavior (Volkmar, 1987). Consequently, it appears that there may be prognostic utility in examining the roots of social behavior, namely the demonstration of attachment in children with autism.

If we are to examine the manner in which children with autism demonstrate attachment behaviors, it is important to examine current research findings in this area. Presently, there is some debate about whether or not children with autism form differential attachments. Researchers such as Dissanayake and Crossley (1997) and Sigman and Mundy (1989) suggest that individuals with autism are capable of differential attachment, while others disagree (Cohen, Paul, & Volkmar, 1987). The majority of researchers in this area have utilized the Ainsworth Strange Situation (Ainsworth et al., 1978) to measure attachment in autism. Given the differences in research findings, it may be that there is a need to explore attachment in autism through a different lens, perhaps using a more qualitative perspective. It may be the case that attachment can not be examined or measured in the same manner as it is with normal children or with other clinical populations. In the section to follow, the notion that attachment in autism may present itself as qualitatively distinct from other forms of attachment behavior will be examined. Moreover, the prognostic utility of such an argument will be outlined.

If one is to examine the meaning of "qualitative" in terms of autistic disorder, it may indicate that normal development pathways can not necessarily be utilized in the understanding of the disorder. That is, the developmental progression of autistic children may be qualitatively different than that of normally developing peers (Wenar, 1994). As Wenar (1994) stated, "qualitative impairments in autism could mean that autistic behavior has no counterpart even in the behavior of younger, normal children and that the developmental sequencing of behavior does not follow that charted for normal children" (p. 107). Moreover, if the patterning of behavior is unique to autistic disorder because of the qualitative impairments in cognitive, social, and communicative functioning, it appears likely that these impairments may contribute to qualitative differences in the development of attachment relationships. Further examination of the *quality* of the attachment relationship may be necessary in order to determine the nature of attachment behavior in autism, and consequently, the prognostic result of such an attachment.

Next, Attachment item C was negatively related to self stimulatory behaviors in autism. To be more precise, children with self stimulatory behaviors demonstrated less attachment behavior. There are various plausible explanations as to why this may have occurred. To begin with, communication skills are necessary for a child to be able to address a familiar other. Challenges with language would make it almost impossible for a child to effectively complete such a task. It could be the case that children who are unable to reach out to others by using their name are not able to access caregiver comfort. As such, children with limited attachment behaviors may rely on self-stimulatory behaviors to compensate for the lack of proximal contact with a primary caregiver. That is, children with autism may display self stimulatory behaviors as a means to address their lack of social contact with their primary caregiver. For instance, rocking is a commonly observed self stimulatory behavior in children with autism (McBride and Panksepp,

1995). It is also regarded as a soothing behavior in normal children. More specifically, some mothers use the rocking motion as a way to comfort their infant child. Perhaps children with autism, who are unable to effectively gain the attention of their caregiver, are forced to soothe themselves.

It is also interesting to note that the severity of the disorder was found to be negatively related to Attachment item C. Children with more severe forms of autism were found to demonstrate less attachment behavior. This appears to support Mathijssen et al. (1998) findings that positive parent-child relationships are associated with less severe problem behavior. Moreover, it is possible that children with severe forms of autism experience significant challenges in addressing a familiar person as a result of the severity. After all, the level of communication impairment is one of the factors which is considered when severity is determined.

Research Question Two

Research Question two explored the domain of behavioral disturbance, namely, which types of behaviors were most associated with outcome. Rigidity was found to have a negative relationship with prognosis in the area of communication. Children demonstrating rigid behaviors appeared to make less gains in communication than children without such rigidity. This finding is supported by Wing (1981) who stated that limited flexibility in play and imagination may relate to deficits in the development of language abilities. Other researchers have also found rigidity in play-related activities. For instance, Sigman and Ungerer (1984) demonstrated that the functional and free play skills displayed by children with autism were less diverse than that displayed by matched controls. As an example, children with autism appear to be unable to attribute animate characteristics in various play activities (Dawson, 1992). Given

that flexible thinking (e.g. use of pronouns) is necessary in language development, it appears logical that rigidity may negatively impact language acquisition.

As well, it is plausible that the presence of rigid behaviors may interfere with children's openness to experience and therefore, their ability to take in the social and communicative learning cues in their environment. The inflexibility associated with rigidity may also have a serious effect on their learning process because it has the potential to limit not only the information learned, but the manner in which it is acquired. For instance, if a child is reluctant to attempt a new task, or will only complete tasks in a particular way, then rigidity could lead to adverse effects in the acquirement of language and other skills.

Children with rigid behaviors may avoid social contact as social interactions tend to be quite unpredictable. As such, children with rigid behaviors may be more likely to be classified as "aloof" rather than passive or active-odd (Wing & Gould, 1979). According to Wing and Gould (1979), children in this group have the most challenges with communication. In terms of rigidity, they also show the most impairment in symbolic play activities, which has been previously reported to affect the development of language (Wing, 1981). Given that social behaviors can impact the development of language (Volkmar, 1987), it appears logical that the incidence of rigid behaviors could be linked to decreased social skills. Such difficulties in socialization may, in turn be related to additional challenges in communication skills.

In relation to treatment, it is imperative that rigidity in communication be addressed. Moreover, it appears logical that the specific rigid behaviors of each child need to be examined in the context of communication. For instance, Prizant and Schuler (1987) provide suggestions for dealing with a particular type of rigidity in the language of many autistic children, namely echolalia. Children with echolalia repeat the speech of others in a repetitive fashion, either

immediately after someone has spoken or after a period of delay. According to Prizant and Schuler (1987), such rigidity should be dealt with in an individualized manner. It is also recommended that practitioners respond to the echolalia, in order to teach the child that communication is intentional. It is further recommended that children be assisted in breaking down the echolalic utterance and that punishment never follow a child's interactive use of language, even if echolalic in nature. Taken together, these treatment suggestions could assist practitioners in teaching children with autism to use language in a more flexible manner.

When examining other behavioral disturbances such as self-injurious behavior, self-stimulatory behavior, and aggression towards others, trends were detected in children who did not display such behaviors. Although these trends were not found to be statistically significant, it is important to consider why the absence of specific behavior problems was associated with more positive mean ratios of monthly gains. It could be argued that behavioral disturbances are positively associated with severity in autism. Hence, it is also plausible that specific behavior problems are critical to prognosis. For example, aggression towards self can be viewed as a form of social disturbance in that it negatively impacts social relationships. Given that social interactional style appear to be related to prognosis in children with autism (Volkmar et al., 1996), it seems fair to postulate that aggression towards self could lead to difficulties in establishing social relationships and consequently a poorer prognosis.

Given that there appears to be some relationship between problematic behaviors and prognosis in children with autism, it is critical that behavior modification be an emphasis of treatment. That is, the treatment curriculum should focus on the elimination of behavioral disturbances and the development of more socially appropriate behavior patterns. As an example, the use of a reward/punishment behavioral approach could be used to reduce the

incidence of rigidity. Or, it may be conceivable to incorporate other types of behavioral strategies to deal with problematic behaviors observed in autism. According to Lovaas (1987), if a child's environment can facilitate the development of strategies for adaptive learning, it may be possible for a child to overcome behavioral tendencies (Lovaas, 1987).

Research Question Three

Research question three examined the relationship between the severity of autism at time of the initial assessment and outcome. Severity was demonstrated to have a significant relationship with outcome in terms of adaptive functioning. That is, the more severely autistic children tended to demonstrate less progress on the measure of adaptive functioning administered. There are number of potential reasons for this finding. To begin with, children identified as severely autistic may experience more challenges with adaptive functioning because of the severity of their autistic symptomatology. It may be the case that the autistic symptoms impede the child's ability to perform even the most rudimentary tasks in an independent fashion.

In the current study, mental retardation was also found to be correlated with severity. It could also be that an inverse relationship exists between severity and IQ (i.e. more severe autistics demonstrate lower IQ). Such a relationship could explain the many obstacles and impairments in adaptive functioning, given that IQ is the benchmark of mental retardation. Furthermore, adaptive functioning and IQ are related in that a diagnosis of mental retardation requires that both cognitive ability and adaptive functioning fall significantly below normative levels.

Past research has demonstrated the relationship between the severity of autism, IQ and outcome (Lotter, 1974, 1978; Volkmar, 1996). For instance, Volkmar (1996) found that children more severely afflicted with both autism and mental retardation were less likely to make

substantive cognitive gains. In terms of prognosis, such a relationship appears to explain the impairments in cognitive functioning (See hypothesis five for further discussion of IQ and mental retardation).

Research Question Four

Research question four examined age of diagnosis and whether or not a relatively early diagnosis (i.e. before the age of three) was predictive of functional gains. In this study, early diagnosis was not found to be associated with a better prognosis. However, it is important to explore possible explanations why this hypothesis was not supported by the current study. Firstly, Klinger and Dawson (1996) noted that early diagnosis is essential in that it allows for an early intervention to be established. However, it is possible that there may have been a delay between the time of diagnosis and the commencement of treatment for the children in the current study. Most children in the sample were diagnosed at the Alberta Children's Hospital before being referred for treatment. After the diagnosis was made, parents were provided with information regarding treatment. Once parents decided which treatment option to pursue, they typically underwent some form of assessment at time of intake. Given the number of staff available at STA-EIP, it is also important to consider the possibility that not all children were screened and accepted into the treatment process immediately after the diagnosis was made. The time lapse between the time of diagnosis and the actual time of intervention may have varied considerably between children. Thus, the transition between early diagnosis and early intervention may not have been expedient as the literature implies. It is evident that some of the children in the sample did not begin treatment during the first three years of life, which has been documented to be crucial for the development of social behaviors and language (Dawson, 1992; Lovaas, 1987).

Another possible reason why the hypothesis regarding early diagnosis and outcome was not supported could be due to advancements in treatment. In the past ten years, intervention programs for children with autism have become more individualized. Moreover, there is much research to guide practitioners in their choice of treatment goals. Thus, when considering prognosis, the nature of treatment programs may be more important than early diagnosis. Such an argument would be supported by Dawson and Osterling (1996) who have examined the outcomes of many intervention programs. According to Dawson and Osterling (1996), not all programs emphasized the imperative nature of early diagnosis and subsequent treatment, and yet similar outcomes were found across such intervention programs. Rather, it was discovered that various treatment programs for autism all incorporated core elements in their curriculum. Such core curriculum could then account for similar outcomes, regardless of early diagnosis.

In addition, it is important to consider the possibility that, given the small sample size utilized in the present study, it may be the case that differentiation between children diagnosed before and after the age of three was not established. Therefore, it is imperative that researchers further investigate this area in order to affirm, or disconfirm the prognostic utility of an early diagnosis and subsequent early intervention.

Research Question Five

Research question five examined whether or not factors associated with medical and mental conditions were associated with prognosis. First, mental retardation (MR) was found to be significantly related to gains in cognitive functioning, adaptive functioning, communication skills and overall functioning (i.e. a combination of cognitive functioning, adaptive functioning, communication skills and autistic symptomatology). Children with mental retardation were

found to have demonstrated significantly less mean monthly ratio of gains than children without MR.

To clarify, children with mental retardation have an IQ substantially less (i.e. >70) than what is determined to be in the normal range (i.e. average IQ = 100, with a standard deviation of 15). According to the empirical literature, higher IQ has been found to be predictive of better outcome (Stone, Maclean, & Hogan, 1995; Volkmar, 1996;). Therefore, it appears logical that those children identified with MR were reported to have reduced mean monthly ratios of gains in the areas of cognitive, adaptive, and communicative functioning, as well as overall functioning. Within the sample in this study, 77% of participants in this study were identified as mentally retarded. Additionally, differences in IQ existed, ranging from mild to profound mental retardation. However, it is important to note that the presence or absence of mental retardation was coded, not the specific degree of retardation. Therefore, it was not possible to determine the relationship between different levels of retardation (i.e. mild, moderate, severe) and outcome.

Other health conditions (e.g. asthma, ear infections, birth complications) were not found to be significantly related to outcome. However, non-significant trends were detected. Given the small number of children reported to have such comorbid illnesses in this study, it is possible that differences between children with or without such illnesses were not found. Further research in this area is necessary in order to better explore the potential effects of comorbid disorders and conditions and their effects on prognosis and outcome.

It is surprising that, out of this sample of children with autism, 17 were documented to have recurrent ear infections. According to Crook (1998), Candida, a yeast-related toxin is thought to be connected to autism, which may account for the reoccurrence of ear infections. Crook (1998) delineates that “almost without exception, autistic symptoms in these children first

appear during the second and third years of life following repeated ear and other infections” (p. 153). Although, the work of Crook (1998) appears to be interesting and definitely presents a plausible explanation for the relatively high number of children with recurrent ear infections in this current study, more empirically validated research needs to be conducted in order to support such an association. Also, it would be important to explore the relationship between hygiene and ear infections in the autistic population, as poor hygiene could result in wax buildup, which could, in turn, lead to more ear infections. Such recurrent ear infections could also impact a child’s ability to communicate with others, given the potential auditory challenges associated with ear infections. Additionally, children with autism may be less able to effectively communicate discomfort, which could result in the progression to more severe infections.

Research Question Six

In regards to research question six, gender was found to be significantly related to gains in the adaptive functioning domain. Moreover, it is important to note that the number of females to males ratio in this study was consistent with that reported in the empirical literature, which states that for every female with autism approximately three to five males are affected (Klinger & Dawson, 1996). Female participants in this study demonstrated lower mean ratios of monthly change in adaptive functioning than males. This finding is supported by the literature regarding gender differences in autism, which states that with uneven sex ratios, the lower prevalence sex tend to be relatively more severe (Cicchetti & Cohen, 1995; Taylor & Ounsted, 1972; Tsai & Beisler, 1983; Tsai et al., 1981). Taken together, it appears that a male child with autism has a greater likelihood of making gains with regards to adaptive functioning, and therefore a better prognosis.

It is interesting to note that gender was not found to be significantly related to gains in other areas of functioning (i.e. cognitive, communication, autistic symptomatology, and overall functioning). It may be that the distinction did not emerge because of the small number of female subjects included in this sample (i.e. eight females to 31 males). Additionally, three of the eight females included in this study scored in the mild range of the Childhood Autism Rating Scale at the time of intake. Given that the lower prevalence sex tends to be more severely afflicted, it is possible that the female subjects included in this study were not representative of the population of females with autism. Nonetheless, additional research in this area is necessary in order to better understand the prognostic utility of specific deficits associated with gender.

Research Question Seven

Lastly, research question seven explored the relationship between developmental milestones and prognosis. It was discovered that language milestones, specifically the age of a child's first word was significantly related to overall functioning (i.e. a combination of the domains of cognitive functioning, adaptive functioning, communication skills and autistic symptomatology). Children who developed their first word before the age of one demonstrated higher mean monthly ratios in overall functioning than children who developed language after age one. It may be that these particular children (i.e. those found to have a first word before age one) followed the normal developmental course of language development up to a certain age. This, in turn, may have impacted other areas of functioning. Such an assumption is substantiated in Lotter's (1974; 1978) research, which found the presence of functional language by age five to be one of the most potent predictors of prognosis in autism. Expressive language by age five was also determined to be the most powerful predictor of behavioral and vocational outcome. Moreover, it was discovered to discriminate between lower and higher functioning children with

autism (Lord & Paul, 1997). Although the five year time period was not utilized in this study, the researcher believes that the demonstration of expressive language skills before age one is indicative of normal language development (Wenar, 1994). It appears logical that the attainment of such a developmental milestone during the normative period would increase the likelihood for a better prognosis. In addition, the prognostic power of such a developmental milestone may overshadow the importance of attaining other developmental milestones in a timely fashion. This may explain the reason why other milestones were not demonstrated to be statistically significant in this study. Or, it could be the case that other developmental milestones (e.g. first steps) typically follow a more normal developmental course in children with autism. However, more research is needed in this area in order to consider such a possibility.

Concluding Remarks

In examination of the results of the current research, it is evident that two significant themes emerged. The development of expressive communication skills and the level of cognitive ability appear to be the most critical variables in terms of prognosis. As such, these variables should be considered in relation to treatment. First, the current results suggest the importance of addressing the language deficits associated with autism. Three of the five core curriculum components recommended by Dawson and Osterling (1996) incorporate language. These include the ability to: 1) comprehend and use language, 2) attend and respond to environment cues, and 3) socialize with others. What tends to differ across intervention strategies is the manner in which communication skills are taught. In order to increase the prognostic utility of this core curriculum in treatment programs, such emphasis on language should continue, and ultimately take precedence over other non-verbal aspects of treatment curriculum (e.g. teaching of self-care skills). Further research will need to be conducted in order

to explore the impact of communication training on prognosis and the factors which are related to the development of functional speech (i.e. specific teaching strategies).

Furthermore, it was also found that cognitive ability was significantly associated with prognosis. Given that approximately 75% of individuals with autism are also mentally retarded (Volkmar, 1996), this finding poses as a challenge. In terms of treatment, it appears likely that children without MR will make more substantive gains in functioning when compared to children with MR. It is possible that having more intact cognitive abilities allows some individuals with autism to learn effective methods of compensating for their deficits. Such a finding supports the postulation that prognosis in autism is variable because of the apparent diversity within the population (Gillberg, 1990). Nonetheless, it is clear that for those autistic persons with more severe cognitive impairments, outcome remains discouraging.

Limitations of the Current Study

The limitations of the current study can be broadly classified into two groups: limitations related to generalizability and measurement-related limitations. To begin, it is difficult to generalize the results of the study, given the small number of participants. The number of variables examined far exceeds the number of subjects necessary to conduct statistically sound research (i.e. ten subjects for every variable). However, it is important to note that given the epidemiological nature of the disorder (i.e. 1 out of every 1000 child affected, Volkmar et al., 1997), the sample size of this study can be considered sufficient.

Another limitation of the present study is that it employed a sample which was not diagnostically homogeneous. That is, the children in this sample were diagnosed with autism or Pervasive Developmental Disorder (Not Otherwise Specified). Therefore, the findings of this study can only be generalized to similar samples, (i.e. to a diagnostically heterogeneous sample).

Another factor which limits the generalizability of the present study is that all of the children in the sample were from a single treatment program. Yet, it is important to consider that each child required repeated assessments to be considered eligible for this research. Such a requirement is not easily attainable in a clinical sample of children with autism.

Additionally, it is important to address the limitations of the present study related to measurement. First, some children received different measures of ability at different times or assessments (e.g. utilizing the Bayley Scales; Bayley, 1993 instead of the Arthur Adaptation of Leiter International Performance Scale; Arthur, 1949 when assessing cognitive ability). That is, for clinical reasons, the same assessment tools were not consistently utilized across children at STA-EIP. Structural differences between tests measuring each area of functioning need to be considered in terms of their relationship to prognosis. Moreover, it should also be noted that a different number of possible tests were utilized to determine mean monthly gains within each area of functioning (i.e. four tests for cognitive, one test for adaptive functioning, four tests for communication domain, and one test for autistic symptomatology). This also limits the structural consistency of measurement across domains. Lastly, given that assessments were performed and measured at different time periods for different children and that the differences in time periods between assessments varied (i.e. some children ratios were calculated at intake and middle assessments, while others were calculated at intake and discharge assessments), prognostic results may have been affected.

Suggestions and Implications for Further Research

The information gathered in this study provides direction for future prognostic research in autism. Although exploratory in nature, the present study suggests possible avenues for future research. Additional information regarding the factors which are related to prognosis could lead

to a better understanding of the etiology of the disorder. A clearer understanding in the area of health related concerns and disorders could allow researcher to form stronger etiological links between autism and associated disorders. Such information could, consequently, facilitate changes in medical and drug-related treatment options. For instance, it may be necessary to utilize a specific combination of treatment strategies (i.e. behavior modification with drug therapy) to better assist the unique needs of children with autism. It may also be beneficial to examine the relationship between specific comorbid conditions/disorders in autism and prognosis. However, larger numbers of children with such comorbid conditions is necessary in order for clearer conclusions to be drawn. In terms of prognosis, it could be that certain comorbid health condition/disorders in autism are indicative of poorer prognosis. Thus, a better understanding of the relationships between autism and associated conditions needs to be explored in future research.

In relation to treatment, better comprehension of prognostic factors could also augment the constitution of current treatment programs. For instance, it was found that the stressor of divorce was significantly linked to communications skills. With such information, researchers and therapist alike could work together to develop a treatment curriculum, which would better address the impact of such a stressor. Other family stressors could also be explored in terms of their effect on outcome. Given that caring for a child with autism considerably effects the family as a whole, it may be necessary to examine what treatment strategies could be used to assist the family. Perhaps a family systems approach to therapy should be added to current intervention programs in order to improve family functioning (Harris, 1982). Additionally, further information needs to be gathered in the area of attachment in autism in order to determine its prognostic utility. A clearer understanding of the attachment patterns of children with autism

could provide a framework for researchers to better comprehend the enigma of the social abnormalities inherent in autistic disorder. Future researchers may need to explore alternative methods of measuring attachment in children with autism (i.e. other than the Strange Situation Paradigm) in order to better assess the attachment behaviors of children with autism. Such understanding could have substantial prognostic utility. In addition, it may be helpful to identify potential differences in attachment behavior within the autistic population. Such differences could also be found to impact prognosis. Furthermore, it may be the case that the quality of attachment behavior differs with the severity of the disorder or with the presence of specific behavioral disturbances. Such information could be of considerable value when exploring outcome in children with autism.

Next, given that social impairment is the hallmark of autism (Lord, 1993), the treatment of social deficits should continue to be formally addressed in intervention programs. In order to facilitate the treatment of socialization deficits in children with autism, it may be necessary to incorporate the social classifications of Wing and Gould (1979) in both assessment and treatment. That is, a screening tool for determining where children lie in terms of these classifications may be useful in determining the most appropriate intervention programs for dealing with each child's social challenges. For instance, if a child were identified as "aloof", this may give information regarding the most effective form of social intervention to provide in treatment.

Early identification of autism should also continue to be explored in relation to prognosis and outcome. Such identification may be facilitated by the determination of normative, delayed, or deviant developmental milestones in children with autism. In the current study, the milestone of first word was found to be related to mean monthly gains in the combined areas of cognitive

and adaptive functioning, communication skills, and autistic symptomatology. Given that language development has been documented as a powerful prognostic predictor, it would be beneficial for researchers to utilize such a developmental marker in the early identification of autism. For example, the use of an early language developmental milestone could be added to the criteria of the Checklist for Autism in Toddlers (CHAT) (Baron-Cohen et al., 1996), which is currently utilized in some European communities to screen for autism.

As well, it is also important to consider the potential utility of identifying which children are most likely to benefit from treatment services. Given the reality of waiting lists and the limited number of treatment providers, it is important for professionals and policy makers to ask themselves “who should get what, and why”. That is, it may be the case that less severe children, who can demonstrate that their abilities may be considerably altered by receiving intensive treatment programs should receive additional benefits. This is not to say that some children with autism should be deprived of treatment. All children with autism and their families should be entitled to treatment and support services. However, it may be more cost-efficient to allocate funds for specific treatment services (e.g. behavioral psychotherapy programs) to children demonstrating a greater likelihood of better prognosis.

Lastly, it is necessary to examine prognostic factors and their impact over time. Such longitudinal research may allow for more specific conclusions to be made regarding the prognostic factors associated with positive outcome in autism.

Summary and Conclusions

To summarize, the current study attempted to determine which factors were related to prognosis in children with autism. The domains of family variables, the presence of behavioral disturbances, severity, age at time of diagnosis, health conditions and mental disorders, gender,

and the age of acquisition of developmental milestones were identified as potential prognostic factors. More specifically, the purpose of the study was to explore which prognostic factors were associated with positive outcome in the areas cognitive functioning, adaptive functioning, communication skills, autistic symptomatology and overall functioning (i.e. these four areas combined). Psychometric assessment tools were used to measure gains in each domain.

The thirty-nine participants (i.e. eight females, 31 males) in this study received either 1) an intake, middle and discharge assessment, 2) an intake and middle assessment or 3) an intake and discharge assessment. The mean ratio of monthly gains was determined by taking the difference between assessment scores at time one (intake) and time two (middle or discharge assessment) divided by the child's age at the time of the assessment.

The results of this study revealed that certain prognostic factors were significantly associated with outcome in autism. Attachment items taken from Socialization Domain (i.e. Interpersonal Relationships subdomain) of the Vineland Adaptive Behavior Scales: Classroom Edition (Sparrow, Balla, & Cicchetti, 1984) were found to be positively correlated with each other, as well as with mental retardation, self stimulatory behavior, and severity of autism. Gender was demonstrated to be significantly related to adaptive functioning, as males revealed higher mean monthly ratios of gains in this area. The presence of rigidity was also found to have a negative relationship with gains in the communication domain.

Univariate analyses found that Attachment item C was related to increases in cognitive, adaptive, and overall functioning. Children with the ability to address a familiar other were reported to have higher mean monthly ratios of gains in these three areas of functioning. Children from divorced families were also found to have lower ratios of monthly change in the area of communication skills. Mental retardation was related to adaptive functioning, as children

without MR demonstrated higher mean ratios of change in this particular domain. Rigidity was also found to be related to communication skills, as children without such rigidity were found to have higher mean ratios of monthly change. Lastly, severity of autism was related to adaptive functioning. More severe children were found to have lower mean ratios of monthly change.

Multiple regression analyses revealed that certain family variables, behavioral disturbances, severity of autism, comorbid mental disorders, and developmental milestones were significantly related to mean monthly ratios of gains in functioning. Similar results to the univariate regression analysis were found in multiple regression analysis. That is, children from intact families demonstrated higher ratios in communication skills. Presence of rigidity was demonstrated to be negatively linked to communication skills in this analysis. Also, more severe children were identified to display lower mean monthly ratios of gains in adaptive functioning. Further, it was revealed that mental retardation was negatively related to cognitive functioning, adaptive functioning, communication skills, and overall functioning. Finally, the age of a child's first word was found to be positively linked to gains in overall functioning.

Concluding Statement

Examining the factors associated with outcome in autism allowed the researcher to gain some understanding of why certain autistic children fair better than others. Given that a great deal of diversity exists within the autistic population, it is difficult to definitively answer such a question. Nevertheless, it is evident that prognosis research has the potential to provide a clearer understanding of the perplexities of autism. Moreover, it may likely impact the development of more effective treatment methods. For these reasons, it is imperative that outcome research be continued.

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Appendix A

DSM-IV Criteria for Autistic Disorder*

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- A. Total of at least six times from (1), (2), and (3), with at least two from (1), and one of each from (2) and (3):
- (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple, nonverbal behaviors such as eye-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (d) lack of social or emotional reciprocity
 - (2) Qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal either in intensity or focus.
 - (b) apparently compulsive adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age three: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. Not better accounted for by Rett's disorder or childhood disintegrative disorder.
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*Taken from the American Psychiatric Association (1994).

Appendix B

Cover Letter

Dear Research Director: The Society for Treatment of Autism's Early Intervention Program (STA-EIP):

My name is Lesley Deprey. I am a graduate student in the Department of Educational Psychology at the University of Calgary, conducting a research project under the supervision of Dr. Lauran Sandals and Dr. Kim Ward, as part of the requirements towards a MSc. degree. I am writing to provide information regarding my research project (Prognostic Factors in Children with Autism: An Exploration) so that you can make an informed decision regarding your participation.

The purpose of the study is to determine the factors which affect prognosis in children with autism. These factors will be determined by examining the files which currently exist as part of a larger archival data set at your Center.

Participation in this study will involve no greater risks than those ordinarily experienced in daily life.

Data will be gathered in such a way as to ensure anonymity. Only data pertinent to the present study will be accessible to the researcher. As well, a completed application form has been completed granting the researcher a position as a volunteer research assistant. An oath of confidentiality has been signed by the researcher. In addition, a security clearance form has been filled out and a child welfare record check has been completed.

All subjects will be coded by number once the information is retrieved from the archival data set. Once collected, data will be kept in the strictest confidence, as all files will remain locked in file cabinets at the Center. Only group results will be reported in any publication studies. The raw data will be kept in a locked file cabinet and remain as part of the larger archival data set at the Center after the completion of the study.

If you have any questions, please feel free to contact me at 282-3473, my supervisors at: Lauran Sandals 220-5651 (supervisor), Kim Ward 253-2291 (co-supervisor), the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626, or the Office of the Vice-President (Research) at 220-3381. Two copies of the consent form are provided. Please return one signed copy to me and retain the other copy for your records.

Thank you for your consideration.

Sincerely,

Appendix C

Consent for Research Participation

I, the undersigned, hereby give my consent to participate in a research project entitled Prognostic Factors in Children with Autism: An Exploration.

I understand that such consent meant that I will allow the researcher, Lesley Deprey, access to the archival data set which currently exists at the Center.

I understand that this study will not involve any greater risks than those ordinarily occurring in daily life.

I understand that the data obtained will be gathered anonymously and kept in the strictest confidence.

I understand that only group data will be reported in published reports.

I have been given a copy of this consent form for my records. I understand that if I have any questions I can contact the researcher at 282-3473, my supervisors: Drs. Luran Sandals (supervisor) at 220-5651 and Kim Ward (co-supervisor) at 253-2291, the Office of the Chair, Faculty of Education Joint Ethics Review Committee at 220-5626, or the Office of the Vice-President (Research) at 220-3381.

Date

(Signature)

Research Director's Printed Name

Appendix D

Items Taken From the Diagnostic Checklist for Behavior Disturbed Children, Form E-2*Rigidity: At Least Three of the Following:

Item # 29: Does the child line things up in precise, evenly-spaced rows?

Item # 30: Was there a time before age 5 when the child strongly insisted on listening to certain music?

Item # 32: Was the child fascinated by certain mechanical objects, such as the stove, radio, vacuum cleaner, etc?

Item # 34: Does the child resist accepting new articles of clothing (shoes, coats etc.)?

Item # 35: Is the child upset by certain things that are not "right" (like a crack in the wall, spot on the rug, doors slightly open)?

Item # 36: Does the child adopt complicated "rituals" which make him/her very upset if not followed (e.g. putting many dolls to bed in a certain order, taking exactly the same route between two places, or dressing according to a precise pattern)?

Aggression to Self (Self-Injurious Behavior) and/or Others: Had to Answer "Yes" to the
Appropriate Chosen Response:

Item # 48 Does the child hit, pinch, bite, or otherwise injure himself or others?

~ Yes, self only

~ Yes, others only

~ Yes, self and others

*Taken from Rimland (1984)