

FACTORS RELATING
TO THE PREVALENCE OF AUTISM

A DISSERTATION

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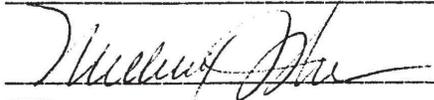
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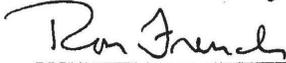
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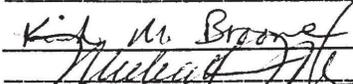

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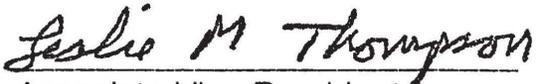






Dean, College of Education
and Human Ecology

Accepted


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DEDICATION

This research is dedicated to my father, Robert Spencer, and to the memory of my mother, Therese Spencer. Their unconditional love and support are the sustaining forces of my life.

ACKNOWLEDGEMENTS

I would like to express my sincere appreciation to the committee members, particularly Dr. Kinnison, who gave so much time and energy in support of this research project. A special "Thank you" to Dr. Kirk Broome whose knowledge and assistance guided and informed my research.

My children, Whitney, Sara, and Adam, have spent many a night studying with Mom. Completion of this research would not have been possible without their patient love and humor.

This research marks the end of a long journey and countless people have helped, encouraged, and supported me. A special thanks to my dear Bob who walked the last mile with me and to the staff at Starpoint who so willingly and cheerfully gave their warmth, caring, and time.

This work is blessed with the memories of so many special children who crossed my path. I thank them for their strength and beauty; they were indeed my inspiration.

:

Factors Relating to the Prevalence of Autism

Kathleen M. Spencer

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This study examined the relationships between socioeconomic, cultural, and ethnic variables on the rates of autism reported by the states. Each state and The District of Columbia was included in the sample ($N = 51$). A latent structural relations statistical analysis was conducted to analyze the data for goodness-of-fit to the theorized model.

The variables studied as influences on the rate of autism were childhood poverty, ethnicity, access to psychological/psychiatric services, and access to advocacy, specifically geographic access to Autism of America members. The theory tested whether these variables affected the rates of autism reported by the states in their annual reports to Congress. The variables associated with the increased rate of autism included Latino ethnicity as well as access to autism advocacy groups. Using goodness-of-fit statistics to analyze the model, 49 states had a good fit with the proposed model. A modification of the model also found a relationship between the 1994 rate of autism and membership in the Autism Society of America. The perfect fit of the data ($GFI = 1.000$) was in a modification which included all the states and proposed a direct relationship between Latino proportionality in the

population and the rate of autism in 1994. In that model, when the proportion of Latino children is proportionately large, the rate of autism reported by the states is higher ($p < .05$).

These findings have implications for further research and study. The influence of socioeconomic and sociocultural factors on the labeling and education of children should be monitored closely. There is ample evidence to suggest that the disability categories of IDEA are replete with over- and under-representation difficulties. This study would suggest that those same difficulties, particularly ethnicity, may well be influences in the labeling of children as autistic.

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CHAPTER I

INTRODUCTION

Over 50 years ago, Kanner (1985) described 11 children seen in treatment in an article titled, "Autistic Disturbances of Affective Contact." This began the modern study of individuals with the diagnostic label of autism. There has been a tremendous outpouring of attention since that time among professionals and the public in general culminating in 1990 with the addition of autism as a disability category to The Individuals with Disabilities Education Act (IDEA, Title 42, U.S.C. 12101). In the most reauthorization of IDEA (1994), autism is:

a developmental disability significantly affecting verbal and non-verbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. (Federal Register, 1994, p. 44801)

Autism has been found throughout the world in families of all racial, ethnic, and social backgrounds. No known factors in the psychological environment of a child have been shown to cause autism (Autism Society of America, 1995a).

Historically, autism has been considered a color and culture blind disorder affecting all social and ethnic groups equitably (Cohen & Donnellan, 1987), however, this was not a universally held position. The most prominent researcher and theorist, Kanner (1985), at first believed that the disorder was more often noted in middle- and upper-class White families.

This proposition was further advanced by Bettelheim (1967) who posited that mothers of children labeled as autistic were typically White suburban housewives whose attitudes toward their infants were cold and unfeeling. The label "refrigerator mother" became popularized. In the Bettelheim (1967) description of the physical characteristics of the child with autism, the child described was unquestionably White.

This theory or belief has since been discounted or disavowed in favor of the position that people with autism are of all cultures and ethnicities with varying neurological dysfunctions. Most investigators now accept the concept of an underlying organic, though enigmatic, etiology (Cohen & Donnellan, 1987). But does this aged stereotype of autism as a White middle- and upper-class disorder persist? Does this stereotype affect identification?

Perhaps an additional and more probable hypothesis, however, is that the diagnosis of autism is affected by a variety of cultural and societal forces which historically

impact both regular and special education dramatically. These forces have confounded the labeling of children in disability categories.

Poverty and its effects on the education offered to children of poverty is well documented over the past decades (Children's Defense Fund, 1996; Kozol, 1991; Oakes, 1985). The educational experiences of the poor child are vastly different in quality and quantity. Kozol (1991) vividly and poignantly described the educational inequities which exist between the schooling experiences offered to children of poverty and children of privilege.

Race, ethnicity, and family structure are strongly associated with the likelihood of living in poverty (Elam, 1993). Approximately 2 in every 5 African American children live in poverty with 68.7% being born to single mothers while about 1 of every 3 Latino children live in poverty, and 40% are born to unmarried women (Children's Defense Fund, 1996).

Harry (1992a) noted that societal attitudes toward families who live in poverty with cultural, linguistic, and racial differences overwhelm families. The additional stress of a child with a disability only further compounds the difficulties of families. Herman (1983) wrote:

When the three status distinctions of poverty, minority, and childhood exceptionality intersect, the families involved are uniquely vulnerable to systematic discrimination. (p.47)

This pattern of discrimination is well known and currently monitored by The Office of Civil Rights in the

so-called "judgment disabilities" of learning disabilities, mental retardation, and emotional disturbance. These categories are so titled because expert or professional judgment is critical to the labeling itself (Chan & Kitano, 1986). These categories can be differentiated from the "hard" disabilities such as visually impaired, physically handicapped, and others for which discrete, measurable physiological or physical indicators or standards exist.

Autism is certainly a "judgment" disability. Difficulties in differential diagnosis plague psychologists/psychiatrists and the low incidence of the disability serves to limit the experience base of many practitioners. Autism as a diagnostic category is further confounded in that it is seldom a stand-alone disability; about 80% of children with autism also are mentally handicapped and have the presence of a significant speech delay (Autism Society of America, 1995a).

The addition of autism to the disability categories of IDEA has given researchers and educators new opportunities to study prevalence data, identification patterns, diagnostic criteria, and intervention techniques. There is now available a data base of children in the United States identified by a common IDEA definition of autism with requisite annual reporting. Indeed, in the Office of Special Education Programs Seventeenth Annual Report to Congress (1995), autism was one of the fastest growing categories (Kosleski, 1996).

The opportunity to research and verify or discount the influence of ethnicity and poverty as influences on the identification rate of school-age individuals who are labeled as autistic is now possible.

Statement of the Problem

In the Office of Special Education Programs Seventeenth Annual Report to Congress (1995), there is a marked difference in the prevalence or detection rates of autism reported to Congress by the individual states. If the epidemiological studies conducted by Lotter (1966) have stood the test of time as stated by the Autism Society of America, the prevalence rates of the states should be essentially equal (Autism Society of America, 1995b; Lotter, 1966). Given that several years have passed since the IDEA category addition, the rates, in theory, should be virtually identical after the initial diagnostic "catch up" period predictable when a disability category is added.

The historical difficulties in special education with placement and treatment in the so-called judgment disability groups makes the autism diagnosis and the societal influences on the rate of that diagnosis worthy of study. Just as Kanner (1943) noted the social class of and ethnicity of the children he identified, other researchers question whether there is a relationship between social class and selective referral and placement (Schopler, Andrews, & Strupp, 1979;

Tsai, Stewart, Faust, & Shook, 1982). According to Zahner and Pauls (1987), the social class hypothesis remains an arena in which further study is warranted as current epidemiological data are, at best, "equivocal" (p. 205).

The effect of a well-organized, vocal parent and professional advocacy group on detection rate of disabilities has not been studied. The Autism Society of America is the largest group of parents and professionals active in the advocacy movement for people with autism. There are currently about 22,000 members, which represents a 20% increase over the last 2 years (Minor, 1996, personal communication).

Autism Society of America literature states

The mission of the ASA is to promote lifelong access and opportunity for all individuals within the autism spectrum and their families, through education, advocacy, the promotion of research, and increased public awareness, to be fully participating, included members of their community. (ASA, 1995a, p.3)

The effect of access to highly specialized psychological/psychiatric services on the detection rate of disabilities has not been studied. The diagnosis of autism is made, in part, by a licensed psychologist or psychiatrist (IDEA, Title 42, U.S.C. 12101). Therefore, access to these services is critical for diagnostic procedures to take place.

Purpose

The purpose of this study was to investigate via statistical methodology of a LISREL (linear structural

relations model) if variables of childhood poverty, student ethnicity, access to psychological or psychiatric diagnostic services, and access to autism advocacy groups influence the prevalence or detection rates of autism in school-age children in the states. The results may identify whether these variables are of significance in the labeling of children as autistic.

Significance of the Study

This study contributes to an understanding of the role of societal and cultural factors in the identification of children as autistic. Unlike the disability categories of learning disability, mental retardation, and emotional disturbance, the Office of Civil Rights does not keep ethnicity data on the category of autism (Department of Education, 1994). There has been a rapid increase in individuals identified as autistic in the United States as reported to Office of Special Education Programs, yet the characteristics of the population itself intrastate and interstate are not well known (U.S. Department of Education, 1992, 1993, 1994, 1995).

Children labeled as autistic receive different services than those who are not so labeled. For instance, in Texas, the Individual Educational Plan Supplement for Autism specifically adds service considerations not offered any other disability category as a matter of routine. These are

the requirements that the Admission, Review, and Dismissal committee address:

1. extended educational programming;
2. daily schedules reflecting minimal unstructured time;
3. In-home training or viable alternatives;
4. prioritized behavioral objectives;
5. prevocational and vocational needs of students, ages 12 or older;
6. parent training; and
7. suitable staff to student ratio.
(Division of Special Education, 1995, pp. 46-47)

Recent due process hearings in three states held that discrete trial training was the most appropriate educational program for a child labeled as autistic or pervasive developmentally delayed. Schools were ordered to provide as much as 20 hours per week of this type of training to the preschoolers ("New SEA decisions," 1996).

Possibly students with autism are not being identified and given the services they require educationally due to societal and cultural differences. This is an inequitable situation which does not permit the free appropriate public school education to which all children with disabilities are entitled.

Research Questions

The objective of this research was to obtain answers to these questions.

1. Was student ethnicity a significant factor in the prevalence rate of autism in each state?

2. Was the rate of child poverty a significant factor in the prevalence rate of autism in each state?

3. Was access to autism advocacy groups a significant factor in the prevalence rate of autism in each state?

4. Was access to psychological and psychiatric services a significant factor in the prevalence rate of autism in each state?

Definition of Terms

Autism is operationally defined as a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before 3 years of age, that adversely affects a child's educational performance (Federal Register, 1994).

Epidemiology is defined as the study of the distribution and determinants of disease occurrence in populations (Zahner & Pauls, 1987).

Ethnicity refers to a student's ancestry or membership in a group which has common linguistic characteristics, country of origin, or physical similarities (U.S. Department of Commerce, 1990).

Poverty is defined as money income thresholds that vary by family size and composition; these thresholds are derived by a variety of economic indicators (U.S. Department of Commerce, 1990). There are several measures of poverty available to the researcher; the one chosen for this study

was the number of children under the age of 18 living in households with incomes under the established poverty threshold in 1990.

Autism Society of America (ASA) is a group founded in 1965 by parents of children with autism and is now the largest collective advocacy group for individuals interested in autism in the United States (Autism Society of America, 1995a).

Limitations

The data were gathered from educational and governmental sources collected at varied times and under varied conditions. Efforts were made to examine and analyze data by the year of collection or the closest calendar year possible.

Reports drawn from the federal child count have been criticized for placing children in disability categories based on unreliable procedures and are highly inconsistent state to state ("ED flags 'danger zones' for minorities in special education," 1995). Brown, an official at the Office of Innovation and Research in Washington speaking for the Office of Special Education Programs, noted that unreliable reporting affects all special educational categories.

The IDEA report did include children enrolled in public early childhood intervention programs under the age of 6 years as well as children enrolled in private schools when they are placed by the public school system via the

Admission, Review, and Dismissal committee. Private school placements also are not included in this detection study and, therefore, the population of children identified as autistic but not receiving services funded in whole or part under IDEA are not represented by these data. Generally, however, students with autism enrolled in private schools are funded by IDEA; a representative from ASA estimated that over 80% of private school enrollment is funded by IDEA due to lack of appropriate public school programming options (Minor, 1996, personal communication). At present, there is no access to a systematic data base which reflects the number of students with autism outside of IDEA funding.

Children under the age of 6 years can be classified noncategorically, that is, placement in a special education setting does not require specific disability labeling under changes to IDEA in 1990 (IDEA, Title 42, U.S.C. 12101). It is impossible for the researcher to estimate what proportion of this noncategorical population of children are autistic or will be classified as such when they reach the age of 6.

Ethnicity labels themselves limit this study and make distinctions between groups somewhat ambiguous. The labels used by the U.S. Census Bureau are in common practice among demographers, but important caveats must be considered. The label Latino encompasses most Spanish-speaking peoples and includes residents who are Mexican, Cuban, South American, Puerto Rican, and others. Use of the ethnicity label of

African American includes people who are as little as one-sixth African American in their biological inheritance. The Asian/Pacific Islander label includes peoples with a vast variety of racial and ethnic differences (U.S. Department of Commerce, 1990).

CHAPTER II

REVIEW OF THE LITERATURE

This study was concerned with the identification of societal and cultural variables which were significant in the differential detection or prevalence rates of children identified as autistic in each of the United States. The detection rate or prevalence data were based on the reporting by the individual states to the Congress on the implementation of the Individuals with Disabilities Education Act in the years of 1990-1994. The following areas were addressed in the review of the literature:

(a) Epidemiological/prevalence studies in the United States to date, (b) Diagnostic difficulties, (c) Minority populations, (d) Poverty and educational programs, and (e) Advocacy and access to service.

Epidemiological/Prevalence Studies

Epidemiological studies of individuals labeled as autistic are few in number; those that have been reported are dated and have an uneven geographic distribution (Zahner & Pauls, 1987). Several of the best known and most often cited studies were conducted in Europe in years from 1966 to 1983; 6 others were performed in Japan in 1982 and one

was attempted in Africa in 1980 (Zahner & Pauls, 1987). Treffert (1970) conducted one of the few studies in the United States, and it was limited in scope. The count included children labeled as autistic when those students were referred to and diagnosed by mental health clinic practitioners in rural areas of Wisconsin. In a study conducted jointly by University of California at Los Angeles and the University of Utah, the state of Utah had an incidence of 4 in 10,000 which is consistent with previous estimates (Ritvo et al., 1989). Data about identified individuals with autism were gathered from the entire state including private and public schools, mental health facilities and hospitals, physicians, psychologists, and psychiatrists. According to Zahner and Pauls (1987), there is a "surprising" lack of epidemiological research in North America regarding individuals with autism (p. 205). Other than the the university study done in Utah (Ritvo et al., 1989), there has been no large scale prevalence study since that time.

There were apparent similarities in all of these studies. There was a common point prevalence of 4 to 5 /10,000. However, varying methodologies and markedly different and differing diagnostic criteria and/or misdiagnosis make contrasts between them questionable (Zahner & Pauls, 1987).

Currently, the prevalence rate of autism is in dispute. Bryson (1996) estimated that the prevalence of autism is nearly twice the 4 to 5/10,000 or about a frequency of about 10 per 10,000. This rate change is most likely reflects changes and expansion of diagnostic criteria (Bryson, 1996). A prevalence of 15 out of every 10,000 births was recently suggested as more representative of the true incidence at the annual meeting of the American Psychiatric Association (Begley & Springen, 1996).

ASA estimated that there are nearly 400,000 people in the United States who have some form of autism and suggested a prevalence rate of 15 per 10,000 which places it as the third most common developmental disability--more common than Down's syndrome (Autism Society of America, 1995c).

The latest data from the Office of Special Programs Eighteenth Report to Congress of the Implementation of the Disabilities Education Act (1996) is not yet released, but information from Office of Special Education Programs indicate that the number of individuals with autism reported in it rose over 50% in the 1994-95 reporting period from about 15 thousand in 1993-94 to 22 thousand in one calendar year. The state of Oregon has a point prevalence rate in school-aged children of 20 per 10,000; that state rate is the highest in the nation and 2 to 3 times higher than in Mississippi, Alabama, and Florida (Brown, 1996, personal communication).

The Diagnosis of Autism

In the first (1952) and the second (1968) editions of the American Psychiatric Association's Diagnostic and Statistical Manual, the only term available to describe autism was childhood schizophrenia. The third edition (1980) adopted specific, operational criteria and stimulated both research and service provision (Cohen & Donnellan, 1987). As listed in the Diagnostic and Statistical Manual IV (DSM IV), autism is a pervasive developmental disorder; other pervasive developmental disorders include Rett's disorder, childhood disintegrative disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified which includes atypical autism (American Psychiatric Association, 1994).

Cognitive information regarding children with autism is consistent; the usual estimate is that 70 to 80% of individuals with autism also are classified as mentally retarded (American Psychiatric Association, 1994; Autism Society of America, 1995b). Investigators have suggested that the frequency of autistic-like behavior increases as the level of cognitive functioning decreases making differential diagnosis of severely cognitively impaired children problematic (Dahl, Cohen, & Provence, 1986). Almost all children identified as autistic in the early years also

are mentally disabled. Like other disability categories, the diagnosis of autism requires the expertise of many professionals for accurate diagnosis. Professionals often have difficulty discriminating autism from its most common counterpart of mental retardation (Cohen & Donnellan, 1987).

Some research has been completed contrasting test performance of children with autism and children with mental retardation. Rutter and Gamezy (1983) reported that children with autism had more difficulty with sequencing and abstraction with fewer deficits in perceptual organization, spatial performance, and short-term memory. Using a Casati Levine Scale derived from Piagetian theory, children with autism did not differ from their mental-age matched cohorts who were either normal or cognitively impaired indicating they are not delayed in sensorimotor skills at their mental-age equivalent. Diagnostic differences in children diagnosed with both mental retardation and autism can be subtle (Sigman, Ungerer, Mundy, & Sherman, 1981).

Additionally, it is difficult to distinguish between language disorders and autism in early childhood. Researchers also have suggested that the presence of social dysfunction is the most apt way to distinguish the two disorders (Caparulo & Chen, 1977; Paul & Cohen, 1984). Diagnosing an individual with autism accurately is crucial to treatment choices, and differentiating autism from other disorders characterized by autistic behavior can play a major role in

in the behavioral, educational, and pharmacologic treatment and management of the individual (Edwards & Bristol, 1991).

There is agreement that autism is a heterogeneous group of disorders and individuals with autism vary intellectually, behaviorally, and adaptively in severity (Sperry, 1995). ASA refers to autism as a "spectrum" disorder and suggests the Diagnostic and Statistical Manual IV as a diagnostic reference (Autism Society of America, 1995b, p. 3). The reliability of the diagnosis even within the autistic category can be questionable. The diagnosis of autism and atypical autism has been reported to vary significantly across clinicians (Einfeld & Tonge, 1991). Autism could most definitely be considered a "judgment" disability.

To further complicate the diagnostic difficulties, a significant diagnostic discrepancy exists. Age of onset, that is appearance of symptomology before age of 3, is a critical aspect of the diagnosis of autism in the most common classification system, the Diagnostic and Statistical Manual IV of the American Psychiatric Association (1994). The evidence of the epidemiologic studies done suggest that this age of onset criteria is suspect; many cases have been observed that have a later onset but exhibit all of the classic features (Zahner & Pauls, 1987).

ASA is clearly is not aligned with an age of onset delineation stating in their definition only that the disability "typically appears during the first three years of

life" (Autism Society of America, 1995c, p. 3). The current IDEA definition states that autism is "generally evident before age 3" (Federal Register, 1994, p. 44801). No data exist which clarify age of initial diagnosis for school-aged individuals with autism; under the current IDEA guidelines, there is no need for a diagnostic "label" until age six (IDEA, Title 42, U.S.C. 12101).

The prognosis for individuals with autism is an issue of much discussion. Cohen and Donnellan (1987) cited language development by the age of 5 as a critical factor in the prognosis of the autistic individual, thus, consider educational or therapeutic programming prior to age 5 as essential. Lovaas (1993) reported that up to 40 hours of intense behavioral intervention benefits about 50% of children labeled as autistic when treated by 5 years of age. Age of intervention was a factor in a study done by Bryson (1996). Two groups of children with autism from geographically distinct areas were contrasted and a 15-point intelligence quotient discrepancy was found between the groups. The one potential difference between the groups which could account for this marked variation was the fact that the more cognitively able group had received educational intervention before age 5 years.

In an article entitled, "Recovery from autism is possible," Rimland (1994), a parent and well known advocate and scholar in the field of autism, related individual

success stories from the Young Autism Project at UCLA under the supervision of Lovaas. In the same article, the Princeton Child Development Institute was noted for their recoveries of children when those children are treated before the age of 5. It was further stated that the concept of "recovery" is simply too difficult for many professionals to accept; they typically fault the initial diagnosis as inaccurate (Rimland, 1994). Conversely, when Rimland (1993) addressed the education of his own child publicly, he acknowledged the severity and irreversibility of his child's autism.

In the ASA newsletter, there is a paragraph specifically stating that autism is treatable, symptoms can be reduced and life quality enhanced, and that early intervention and diagnosis are vital. This statement is found in every issue (Advocate, 1996). However, in other ASA literature, there is a statement that the "majority" of individuals with autism exhibit some symptoms to some degree throughout their lives (Autism Society of America, 1995c, p. 3). ASA does not particularly advance one mode of treatment and makes available a wide range of information about many treatment options (Minor, personal communication, 1996).

It would seem that the diagnosis of autism as differentiated from other disabilities would be moot in that the law requires all children with disabilities to be given individualized educational plans according to their idiosyncratic needs. Noncategorical labeling should, in

theory, provide any exceptional learner whatever individualized services she or he might require. However, when attempted on a large scale in England and Wales, the abolition of labels complicated and disrupted services to children (Feniak, 1988). Placements were subject to a variety of influences such as parental pressure, classroom size constraints, and gender mixes. Kauffman and Hallahan (1995) believed that labeling is unavoidable if specialized, appropriate intensive educational interventions are to be provided. There are simply differential treatment choices and efficacy issues for differently diagnosed learners.

In the most common diagnostic picture, that of a child with autism and mental retardation, this would certainly make autism appear to be the diagnosis of choice if treatability and overall prognosis could be seen as more positive; as parents contacted via the St John's University autism listserv noted, "Autism is now considered a diagnosis which can change over time." Another noted, "There's some hope. The statement your child is mentally retarded offers no alternative or future." In another post, a parent remarked that the diagnosis of autism provided her child with the applied behavioral analysis he needed to attain skills and that his full scale intelligence quotient had risen over 40 points (Powell, 1996, personal communication; Weinstein, 1996, personal communication).

Minority Populations

Special education mirrors regular education in its differential treatment of minority students historically. There is adequate rationale to suspect that individuals with autism might be subject to the same biases which affect placement decisions for other disability categories. The lack of ethnicity data about this disability category makes this only a supposition.

It is estimated that by the year 2000, over 30% of the U.S. population will be minorities. Historically, ethnic minorities have been at the bottom of the social and educational order putting minority children and adolescents particularly at risk for psychological disorders (Schliebner, 1992). Data from the Office of Civil Rights support this; minority students make up a disproportionate number of referrals to special education programs, particularly those for behavioral and emotional disorders ("ED's IDEA review will include hard look at minority services," 1994).

The issue of over- and under-representation of minorities in special education became prominent with Dunn's article in 1968 and continues to the present. Mercer's (1973) noteworthy study found that minority and socioeconomic status were highly correlated with placement of Anglo, African American, and Latino children in special education classrooms

for students with mental retardation and learning disabilities in California.

Litigation has been instrumental in bringing representation issues to the forefront although rulings have been contradictory. In California, assessment practices have been drastically modified so as to alleviate the problem of over-representation of minorities in special education programs based on what the courts believed was biased testing and assessment practices. Other court decisions have questioned and dismissed the biased testing and assessment issue finding most intellectual assessments to be culturally neutral and not responsible for the minority representations in special education placements (Bierne-Smith, Patton, & Ittenbach, 1994).

Interestingly, variability in over- and under-representation data is idiosyncratic to both the specific disabling condition and the ethnic group. Asian Pacific students are over-represented in programs for the gifted and under-represented in most disability categories; White students are over-represented in programs for giftedness and learning disabilities (Harry, 1992a). Minnesota (1989) estimated that there was a 300% over-representation of Native Americans in special programs for emotional disturbance and a 400% over-representation for African American students. In Florida (Clark, 1985), students labeled as emotionally

handicapped were generally males from lower socioeconomic families, and minorities were over-represented.

Researchers noted that it is difficult to believe that cultural biases did not affect these numbers. In a Dallas Morning News (October 16, 1996) article titled, "Study to look at blacks in special ed," University of Virginia researchers note the minority representation problem in special education and are leading a nation wide effort to examine the minority representation issue, stating that "there is very little research being done about why that is and whether it's justified" (p. 4). Recently, the Southern Poverty Law Center filed a complaint with the Office of Civil Rights, citing problems with African American under-representation in the disability category of learning disabilities. They contended that nearly 7,000 African American students have been denied special education services and alleged that White students in Georgia were 1.7 times more likely to be diagnosed as learning disabled ("Legal trends," 1996).

Meier, Stewart, and England (1989) conducted a large scale study in 174 school districts in the United States to assess race and social class as influences on equity in educational opportunity for African American learners. They found that the sorting practices of schools were associated with ethnicity and that African American students were labeled as mentally disabled at a rate three times greater

than their Anglo counterparts. Data suggested that African American parents were more likely to be quiescent and less visible in the education of their children.

The Department of Education statistics for 1992 quite clearly reflect the same pattern; it was reported that, while 70% of the student population was White, 12% African American, and 13% Latino, the population of students was 65% White, 24% African American, and 8% Latino in special education programs. Interestingly, African American students were over-represented and Latino students were under-represented in the disability categories of learning disabilities, mental retardation, and severe emotional disturbance which are the only categories for which discrete ethnicity data at the federal level is kept ("ED's IDEA review will include hard look at minority services," 1994). It is reasonable to assume that student ethnicity may well influence the identification in the disability category of autism.

Poverty and Educational Programs

Does poverty affect schooling? Houston and Schneider (1994) commenting on The Report Card of American Education (Bennett & Feistritz, 1993), noted that in the ranking of states' educational systems only one state ranked in the top

ten had a significant number of minority children (Minnesota) and that the poverty level of the highest ranking states was low.

Children are the poorest group of individuals in the United States. A child is born into poverty every 32 seconds; a child dies from poverty every 53 minutes. Among the world's 18 most industrialized nations, the United States has the highest child poverty rate (Children's Defense Fund, 1996). Unfortunately, it is impossible to consider many American children without considering the effect of poverty and lack of opportunity in every aspect of their lives, most particularly in schools. This lack of opportunity is expressed in a paucity of materials, poorly equipped and maintained buildings, poorly trained staff, large student teacher ratios, and neglect of special educational needs (Kozol, 1991).

Poor children are 2 to 3 times as likely not to finish high school as are non-poor children, and poor children in school are relegated to inadequately equipped schools and taught by the least qualified teachers. There is a greater likelihood that children who are poor and minority will be taught by less experienced or novice teachers throughout their entire school careers (Children's Defense Fund, 1996). The single best indicator of student performance on the SAT is poverty (Houston & Schneider, 1994).

In a study by Frymier (1992), factors which place

children most at risk in U.S. schools were analyzed; socioeconomic situation, family tragedy, and family instability were three of the five most significant. The socioeconomic situation of the family influenced the child's attendance, rate of gain in academic skills, grade retention, and referral and placement in special programs. Parents were isolated from and generally ignorant of the school situation and had rare interactions.

The linkage between socioeconomic status and disability has been researched extensively. Almost 75% of mild mental retardation is linked to socioeconomic status (Baumeister, Kuptas, & Klindworth, 1990); mild disabling conditions such as mild mental retardation and learning disabilities are associated with socioeconomic indicators. Children of low socioeconomic status were greatly over-represented in classrooms for children with mental retardation and learning disabilities (Gelb & Mizokawa, 1986). In a post hoc analysis done on placement patterns in classes for children with mental retardation and learning disabilities, McDermott (1994) reported that 39% of the variation in prevalence rates could be explained by socioeconomic and tax rate factors in a study involving 92 school districts in South Carolina. In a study conducted in five schools of identified special education students, almost half of the children identified as having emotional disturbance had mothers with less than high school completion and lower than average family incomes.

Children from low socioeconomic families in general were as well over-represented (Palfrey, Walker, Butler, & Singer, 1989).

In the U.S., it is impossible to consider socioeconomic status without considering ethnicity or minority status as well. The poorest children in the United States are minority children; 2 of every 5 African American and Native American children, 1 of every 3 Latino children, and 1 of every 8 White children live in poverty (Children's Defense Fund, 1996).

Advocacy and Access to Service

Hines (1987) defined advocacy as a problem solving strategy to correct among other things, problems in service delivery. Coalitions of parents, educators, and citizens have lobbied Congress and have had a significant impact on federal legislation affecting educational and rehabilitative services and delivery of those services to persons with disabilities. Legislation including the The Rehabilitation Act, Education for All Handicapped Act and its progeny, The Americans With Disabilities Act, are products of concerted, cooperative efforts by citizenry and professionals on the behalf of individuals with disabilities (Moats & Lyon, 1993).

ASA is the largest advocacy group in the United States for people with autism and their families (Autism Society of America, 1995b). There are over 22,000 members and there is a

growth rate of over 20% in the last 2 years. About 40% of the ASA operating budget is designated for information and referral services totaling about \$400,000 in 1995. There are about 60 to 70 calls per day to the toll free number and about 15,000 individuals receive information yearly (Autism Society of America, 1995b).

Individuals who access this service are typically family members of a person with autism or suspected of having autism, medical or school professionals, individuals with autism, ministers, lawyers, and administrators. ASA has kept no data on the ethnicity or socioeconomic status of their callers. Callers have access to personal consultation about the concerns of their child with autism. ASA has not endorsed any particular treatment, but will refer callers and inquiries to a variety of sources regarding specific treatment options. ASA provides an extensive number of training packets concerning treatment options and also will give inquirers information so that they can access service providers in their locale (Advocate, 1996).

But finding appropriate diagnostic and treatment options for children with disabilities is often very difficult. Knitzer, Steinberg, and Fleisch (1990) documented the paucity of services to special needs populations, particularly for those children with mental health issues, stating that "the availability of services also affects identification patterns" (p. 9). Also, "where a child lives has a great deal

to do with whether he or she will be identified" (Knitzer, et al., 1990, p. 8). There is tremendous variability interstate and intrastate in identification patterns and services offered; the difficulty of locating a professional with expertise in the differential diagnosis of autism makes proximity to professionals a concern in proper diagnosis and treatment.

Minorities tend to vary markedly in their access and use of community services or agencies. Stanley (1991) investigated mental health services, length of treatment, and outcomes for thousands of Asian American, African American, Mexican American, and White clients who used a variety of outpatient community-based mental health services. There were significant differences in use and outcomes for these groups. Asian Americans and Mexican Americans underutilized the services while African Americans overutilized the services, but overall had less positive outcomes. Each group had lengthier contacts and better treatment outcomes when the therapists were of the same ethnicity.

McMiller and Weisz (1996) studied 192 African American, Latino, and Caucasian families accessing a community health care clinic. It was reported that African American and Latino families were more likely to seek help initially from their own familial and community resources and only availing the mental health or professional system .37 times as much as their White counterparts. Their apparent reluctance was

considered to reflect their cultural patterns confounded by a lack of awareness of local professional resources.

In another study regarding referral of minority adolescents to professional mental health facilities, findings indicated the adolescents were overwhelmingly referred by either the judicial or educational systems. Minority families rarely sought professional help without an outside impetus. Although the problematic behaviors in their children had been identified, they lacked the resources either of time or money to avail themselves of outside help. Most often, there was a lack of awareness (Takeuchi, Bui, & Kim, 1993).

Weissbourd (1992) investigated the utilization of social agencies, mental health resources, and parent support groups by the families of poor children. It was reported that poor families rarely access community agencies, have fragmented support systems, have few health resources, and access social agencies often only when dire financial or legal situations cause action. This might explain the more likely minority participation in subsistence programs such as food stamps, Aid to Dependent Children, and so forth. The current systems posed financial, cultural, organizational, and language barriers to this population.

The school system varied little from its community counterparts in the treatment of minority and poor families. Lareau (1989) studied ethnographic data contrasting

school and family interactions by both upper-middle-class and working-class parents. School personnel welcomed the middle-class parents more warmly. Middle-class parents had greater educational competence, social status, income and material resources, view of work, and social networks which constituted significant advantages for them in their dealings with school personnel. Working-class parents had the same values and concerns for their children but lacked the resources and dispositions which were critical to the quality of the experiences and the outcomes for their children.

In a landmark 1977 study, psychologists from an urban school system made more contacts with parents of majority (White) parents versus minority (African American and Native Indian). Parents of majority students were offered more alternatives in program placement, counseling, social groups, and other programs while the minority group parents were offered only program placement options (Tomlinson, Acker, Conter, & Lindberg, 1977).

The obstacles that families face in the regular education program are mirrored and exacerbated in special education. The special education process is far from parent-friendly for minority and poor families. Zetlin, Padron, and Wilson (1996) studied Hispanic parents' attitudes toward special education. Parents were alienated by the written communication so relied on by school personnel and felt that the documents were incomprehensible. The documents

were on a 6th grade readability level often making the information regarding procedural rights and special education procedures outside their scope of literacy. Many had attended Admission, Review, and Dismissal meetings and signed the documents but could not explain what the Individual Educational Plan was nor could they explain why they attended the meeting at all. It is unlikely then that these parents would have even the most basic understanding of the differentiation of service offered to a child with autism or any conceptualization of the diagnosis itself. Uninformed parents would most certainly be naive educational consumers in the maze of special education paper and procedure.

Connery (1987) contrasted 22 Anglo and Navajo families' awareness and satisfaction with special education programs. Both groups had relatively low awareness, but the Anglo group had more knowledge of special education law, attended twice as many meetings, were generally more familiar with school procedures, and were better able to describe their child's disability. Navajo parents were satisfied with their child's education, but felt that the testing was culturally biased.

The participation by minority parents in special education programs is less involved and less informed than mainstream parents. Empirical studies done by a variety of researchers and summarized by Harry (1992a) yielded the

following list as common features of minority parent participation:

1. Lower levels of involvement than White counterparts
2. Less awareness of special education rights, procedures, and available services
3. An expressed sense of isolation and helplessness
4. Low self confidence in interaction with professionals
5. Stressful life circumstances that overwhelm parents
6. Need for logistical supports such as transportation, child care, and respite
7. Culturally based assumptions of parents' noninterference in school matters
8. Professionals' implicit or explicit discouragement of parental participation in the special education process. (p.100)

Given the complexity and the relative recency of the autism disability category, it would appear that minority parents who tend to be less informed, could easily have their child be assigned to another less apt or less complete diagnostic category concomitant with possibly less appropriate programming options. Harry (1992a) remarked that parents cannot make choices, particularly informed choices without awareness that choices exist. Placement in special education programs requires informed consent. It is the view of Harry (1992b) that informed consent is virtually an impossibility given current practices. Informed consent for minority parents requires personalized communication in non-confrontational situations with people known to the parent or in places such as the home incorporating open-ended and reciprocal dialogue about the process, the disability,

and the lines of authority between the family and the school. Essential to empowerment is communication, not compliance. In the often difficult differentiation of autism from other disorders, it may well be that majority parents of children with autism are given more consideration and thus perhaps access to the more complex diagnostic and treatment options available for their children.

Mistrust is an issue with minority parents as well. Some parents are less involved with schools simply because they feel that the schools are unwieldy, unfriendly institutions which do not follow through on their commitments (Harry, 1992a). Their own school experiences may negatively color their perceptions of education as well (Olion, 1988). African American parents are often extremely alienated by what they perceive as over-representation of their children in the special education program and often relate placement mistakes. One parent noted that her child had been moved to four different placements in one school year (Zetlin et al., 1996).

Conversely, other minority groups have such a traditional trust in and respect for school authority that it actually deters their participation. In studies of both Mexican American and Puerto Rican parents, it was reported that both groups had overall satisfaction with the educational programs of their children, but participated less than did their Anglo or African American counterparts

(Figler, 1981; Lynch & Stein, 1987). Parents of these ethnicities preferred to stay away from school and had considerably less awareness of school programs.

In an attempt to assist minority and poor families in advocacy, school systems have devised advocacy training programs. Historically, most of these programs attract middle-class parents. This pattern of attendance reflected the system's lack of cultural awareness and emphasized that advocacy or training parents of minority groups must be culturally sensitive (Harry, 1992a). Parent training for Asian and Latino parents has been developed and tested with positive results (Chan, Lim-Yee, & Vandevier, 1985). University-based programs have developed parent advocacy training manuals and student teacher experiences which allow preservice educators to gain sensitivity to cultural issues while educating parents in a culturally appropriate manner (Marion, 1980; Roberts, 1990).

Other issues may well interfere with minority parent participation and advocacy on the behalf of their child. Parents may simply be so economically challenged that survival requires tremendous time and energy; taking time from work to attend school or community meetings regarding their children is costly in that they lose an hourly wage or attendance requires cumbersome or logistically difficult transportation or child care considerations. It is not a lack of interest which limits their attendance or participation;

it is simply a need to prioritize for survival (Kroth, 1985; Voltz, 1994).

Harry (1992a) criticized the "ethnocentrism" of the U.S. professional in schools. The predominantly white mainstream professional staff evades responsibility for special needs students when parents are allowed to remain uneducated or unaware of the parental rights and authority in the special education system. The term "lack of cultural capital" is used to describe minority parents in the special education system (p. 91).

Summary

The review of the literature provided the historical and research framework for theorizing the potential effects that the factors of poverty and ethnicity have on the special educational needs and services provided to children with autism. The factors of poverty and ethnicity have been investigated with regards to issues of over-and under-representation in the diagnostic categories of mental retardation, learning disabilities, and emotional disturbance as well as in gifted and talented programs.

Minority and poor families are not accessing the systems of support in the schools and the communities which could assist them with their children. The systems are remote and culturally separate from the daily experiences and realities of a large segment of this population.

Minorities have a troubled past in the field of education and special education. Litigation has not alleviated concerns regarding representation issues and there is continued evidence that minority children and poor children are given an educational experience and educational opportunities very unlike their Anglo counterparts in many instances. Indeed as Kozol (1992) labeled it - savage inequalities.

Gallagher (1994) noted that the future of special education may well require us to be sociologists and anthropologists as we must be aware that social forces such as poverty and ethnicity are very important in determining the shape of the future. Socioeconomic status and ethnicity have been researched and asserted as possible variables in other areas of special education diagnosis, classification, and treatment. It would seem plausible that they would also affect diagnosis and placement of children with autism. Artiles and Trent (1994) suggested that sophisticated data bases need to be established in special education to continuously document minority student data and clarify issues of representation.

Autism is one of the most recent additions to the disability categories under The Individuals with Disabilities Education Act (1990). There is enough diagnostic and programming perplexity and complexity to warrant scrutiny of identification rates. The research also clearly described the

benefit of early identification and thus, intervention for the population of young children with autism.

CHAPTER III

METHOD

The purpose of this study was to analyze identification data regarding the rates of autism reported by the individual states since 1991-92, the first year that these data were mandated for report to the federal government. The model designed tested the theory that individual state rates of child poverty, ethnicity, access to psychological and psychiatric personnel, and access to the autism related advocacy group of Autism Society of America were significant variables in the varying rates and rate changes in the diagnostic labeling of autism reported by the states to the federal government.

The design of this study was non-experimental using quantitative data. The data was then analyzed using a variable structural equation program or a LISREL (**L**inear **S**tructural **R**elations) program labeled EQS. LISREL is a powerful and complex statistical analysis used in studying presumed causal relations among nonexperimental variables simultaneously performing a confirmatory factor analysis and path analysis. The factors are then less scale specific and more closely approach the variables of interest. The LISREL, EQS, or other causal methods are the method of choice when

researchers are attempting to explain the extent of the influence of one variable on another. LISREL methodology is considered "ideal" for analyzing existing data sets (Keith, 1993).

To perform a LISREL, an informal theory or model is required which specifies which variables are to be included as possible causes and which others are presumed to be results. The theory on which this study was based is presented in Figure 1.

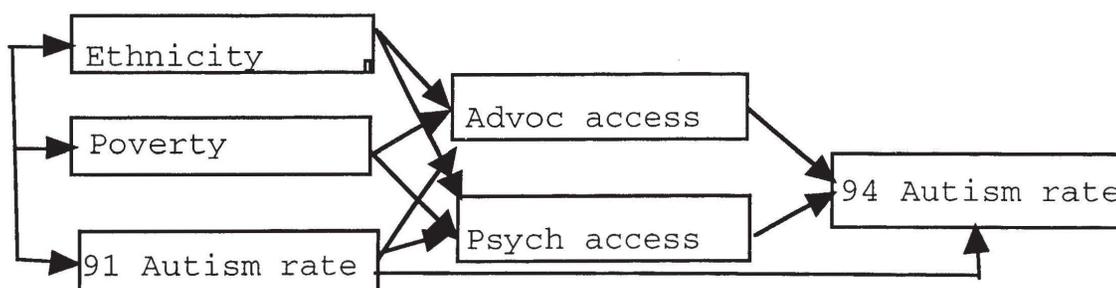


Figure 1. The conceptual model for the influence of poverty, ethnicity, access to advocacy, and access to psychological/psychiatric services on the rates of autism in the U.S.

Data Collection/Derivation

Variables included in the analysis

Initial rate of autism The variable labeled the initial rate of autism was derived from The Fourteenth Annual Report to Congress report of number of individuals labeled as autistic by state and 1990 Census statistical report of the total elementary and secondary school enrollment in the

United States (U.S. Department of Commerce, 1990; U.S. Department of Education, 1994).

Ethnicity The variable of ethnicity was derived from reports from The Children's Defense Fund and the Office of Civil Rights. Ethnicity figures reflected the population of children under the age of 18 (Children's Defense Fund, 1996; U.S. Department of Education, Office of Civil Rights, 1990).

Poverty The variable of poverty was derived from reports from The Children's Defense Fund and the 1990 Census figures. These data represented children under the age of 18 who lived in poverty as defined by the 1990 federal guidelines (Children's Defense Fund, 1996; U.S. Department of Commerce, 1990).

Psychological/psychiatric access The variable of psychologists and psychiatrists per 10,000 population was a direct replication of the figures reported to the 1990 Census Bureau by the American Psychological Association. It was the count of licensed, clinically active psychologists and psychiatrists by state in 1990 (U.S. Department of Commerce, 1990).

Advocacy access The variable of access to advocacy groups was a direct replication of the numbers of members of the Autism Society of America by state in 1992. This data was provided by the Autism Society of America enrollment records (Minor, 1996, personal communication).

Data Analysis

As recommended by Cohen (1990), descriptive statistics such as frequencies and correlations were completed before input into the EQS computer package (Bentler, 1995). The EQS tests structural models testing the relationships both directly and indirectly between the variables as well as the overall fit of the model using the Goodness of Fit Index (GFI) to the data; other goodness of fit statistics were employed as well including the goodness-of-fit chi-square, the Goodness of Fit Index (GFI), Adjusted Goodness of Fit Index (AGFI), and the Comparative Fit Index (CFI).

Each of these goodness-of-fit indexes has differing purposes. The chi-square tests whether the discrepancy between the actual and the implied relationship is significant. The GFI is a coefficient of determination based on the matrix implied by the model; the AGFI adjusts the GFI based on the number of variables in the model. The CFI is a measure of the noncentrality of chi-square measuring the variation from an independence model; that is, if all variables are assumed to be uncorrelated. The best fit is indicated by values that are close to 1.00 for the GFI, AGFI and CFI. The chi-square optimally is insignificant or approaches insignificance.

The theoretical model used for data analysis is presented in Figure 1. This model is based on the theory that

ethnicity, childhood poverty rates, access to advocacy, and access to psychological or psychiatric services affected the detection rates of autism in the states as reported to Congress.

The model tested whether childhood poverty and student ethnicity impacted the rate of growth of the disability category of autism and if factors of access to psychological/psychiatric services and geographic access to advocacy groups are also variables in rate differentials. These variables are tested by the model and iterated as needed to provide the best fit of data to model. The variables of interest are detailed in Appendix A.

Summary

A large amount of data from a variety of governmental and social agencies was used to analyze if the rate of children identified as autistic in each state and in the United States in general is influenced by such variables as ethnicity, childhood poverty, access to advocacy, and access to psychological or psychiatric services. The LISREL program EQS tested the hypothesis that these variables impacted significantly the rates of autism as a disability category of IDEA reported by the states.

CHAPTER IV

RESULTS

The purpose of this study was to examine the relationship between the variables of ethnicity, poverty, access to psychological/psychiatric services, and access to advocacy on the rate changes in the disability category of autism as reported to the government. Data were obtained from a variety of government and social agencies. Data from each state and the District of Columbia was analyzed ($N = 51$). The results of the data analysis are presented in this chapter.

Descriptive Statistics/Initial Procedures

Descriptive statistics were first derived as recommended by Keith (1993). The correlation matrix is reproduced in Table A-1, Appendix B. As expected, there was a significant correlation between African American proportionality in the population and poverty (.469). Noteworthy correlations existed between African American population and psychological/psychiatric access (.442), Latino population and the 1994 rate of autism (.397), and Autism Society of America membership and the 1994 rate of autism (.405). Ethnicity data regarding Asian Pacific Islanders, Native

Americans, and other ethnicities became insignificant in population proportionality analysis when the data were compiled and were omitted from the model (See figure 2).

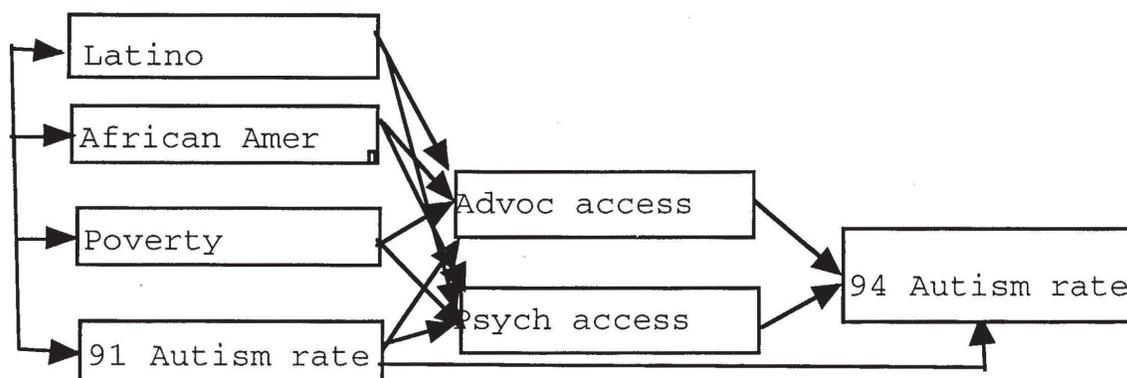


Figure 2. The conceptual model used in Model A and Model B.

It was anticipated that the data would be analyzed using a LISREL 8 Program, but the EQS program (Bentler, 1995) was used as it was a more functional statistical analysis of the proposed model. EQS, LISREL, and other structural relations models are essentially identical (Keith, 1993).

Descriptive statistics were used to describe each of the models used in the analysis. The model was modified three times so four models emerged and goodness-of-fit was analyzed for each model. Each model was derived from information gained at each iteration and, thus, some outliers were identified and removed from one model, while in another model the path was altered.

Statistical Procedures

The first structural model, Model A, analyzed included every state and the District of Columbia. Standardized regression weights are noted on the variable paths (Table A-3). There was marked skewness and kurtosis in four variables. Variable 1, African American had skewness (2.1674) and kurtosis (6.1859), Variable 3, Autism Society of America was skewed (5.5306) with kurtosis (33.0115), Variable 4, Psychological access was skewed (3.9013) with kurtosis (19.0648), and Variable 7, Autism rate 1992 was skewed (3.0080) with kurtosis (10.0556) (Table A-4). Analysis indicated that the cases which had the largest contribution to the normalized kurtosis were cases 9 and 10 (The District of Columbia and Florida) (Table A-4).

Another statistical finding was the possibility that the Latino population had an underestimated relationship in this model as indicated by the large standardized residual (0.310) (Table A-5). The goodness-of-fit statistics (Table A-6) were generally considered a "fair" fit but were affected by the skew and kurtosis brought to the model by the outliers. The chi-square $\chi^2 (4, 51) = 9.964$ was not significant (Table A-6).

Another model was analyzed, Model B. Essentially Model B was identical to Model A, but the outliers of Florida and the District of Columbia were removed from the statistical analysis. Removal of the two outliers in Model B (Table B-1)

markedly improved the skewness, kurtosis (Table B-2), and goodness-of-fit statistics (Table B-3). Goodness-of-fit over .900 is considered a "good" fit of data to the model (Keith, 1993) and Model B met this criteria. The z test score of .651 for the rate of autism in 1994 and Autism Society membership is significant ($p < .05$, Table B-4). The chi-square $\chi^2 (4, 49) = 8.640$ is not significant (Table B-3).

The large residual in Model A (Table A-5) from the Latino variable suggested another path could be added to the analysis to improve the goodness-of-fit (See figure 3). The outliers of Florida and The District of Columbia were omitted from the first analysis of this revised model, Model C, and added again to the last analysis of this model, Model D.

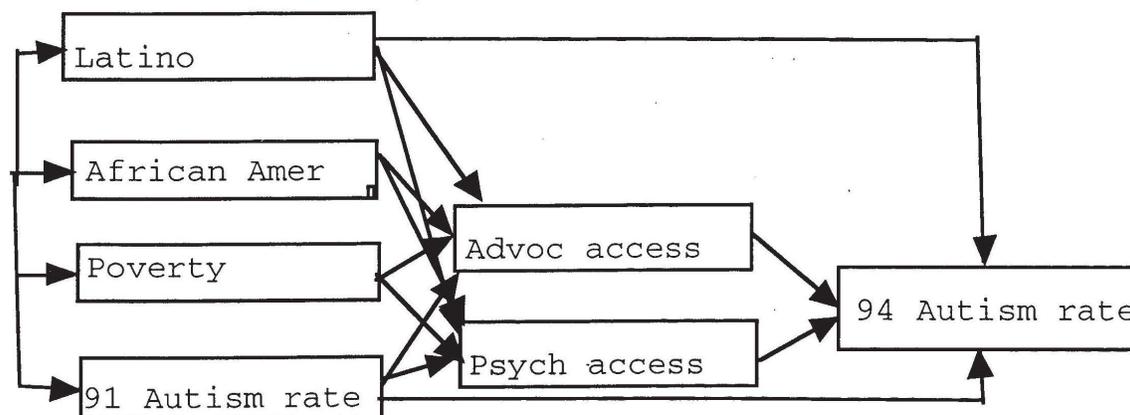


Figure 3. The conceptual model used in Model C and Model D.

Model C did not have a significant improvement in the goodness-of-fit statistics (Table C-2). The chi-square χ^2 (3, 49) = 5.256 was not significant (Table C-2).

Model D used the same structure as Model C but included all the states and The District of Columbia (Table D-1). The goodness-of-fit statistics are excellent; there is a perfect goodness-of-fit (CFI=1.00) and the chi-square χ^2 (3, 51) = 2.326, $p < .05$ was significant (Table D-2).

Research Summary

The purpose of a structural relations model analysis is to test a theory constructed by the hypothesized model (see Figure 1) and the data using goodness-of-fit. The best "fit" of the data to the model was in Model D. The findings indicated that Latino population was the best predictor of an increase in children being identified as autistic in the U.S. and no outliers were removed for this model. In Model D, the chi-square was significant and the Comparative Fit Index (CFI) was 1.000, a perfect fit. The other goodness-of-fit statistic measured was the LISREL GFI which is 0.987, a nearly perfect fit (Table D-2).

The original Model A, had poorer goodness-of-fit statistics due to 2 outliers, namely, the state of Florida and The District of Columbia. These two skewed the results; when removed for iteration in Model B, the goodness-of-fit

improved slightly from 0.846 to 0.943 on the Comparative Fit Index and from 0.950 to 0.954 on the LISREL GFI (Table B-3).

Model C included an extra path from Latino population to rate of autism in 1994 while removing the outliers of Florida and The District of Columbia. The extra path was not significant or necessary as it did not add to the goodness-of-fit of Models A or B (Table C-2).

Model D included an extra path from the Latino population to the rate of autism in 1994, did not remove outliers, and had the best goodness-of-fit of any of the models analyzed. The data derived from Model D indicates that the following could be removed from the model without a decrease in fit: a) the path from 1992 rate of autism to Autism Society of America membership, b) the path from poverty to Autism Society of America membership, and c) the correlation between 1992 rate of autism and poverty (Table D-4).

Findings

The results of this study are organized according to the research questions identified at the onset of the investigation. The research question is stated and statistics are given supporting a research decision.

Research Question 1

Was student ethnicity a significant factor in the prevalence rate of autism in each state?

No models indicated that African American population proportionality affected rates of autism. In Model D where a direct path was tested from the Latino variable to the 1994 rate of autism, the number of Latino students in 1990 was a significant influence on the rate of autism in 19 (Table D-1). The $R^2 = .36$ which indicated that the Latino population could be a predictor of the rate changes in autism. Essentially, the higher the proportion of Latino children in a state or The District of Columbia, the higher the rate changes in the disability category of autism.

Research Question 2

Was the rate of child poverty a significant factor in the prevalence rate of autism in each state?

There was no significant relationship between poverty and the prevalence rate changes in autism. There are influences of poverty in the models. This was observed in Model A where the z value for the association between psychological/psychiatric access and poverty was a -4.110 . Another notable influence of poverty see in Model B where the rate of poverty was highest in states with lower populations of psychologists/psychiatrists (Tables A-7, B-1). Models C and D could remove the path from poverty to the 1992 rate of autism removed with no change to the goodness-of-fit (Table D-4).

Research Question 3

Was access to autism advocacy groups a significant factor in the prevalence rate of autism in each state?

Membership in autism advocacy groups was not a significant factor in the initial rate of autism (1992), but was predictive of autism rate; that is, states with high membership in ASA had a larger rate in 1994. The z test noted in Model A of the path between the variables of 1994 rate of autism and ASA membership rate was 3.390, $p < .05$ (Table A-7). The z score in each model was significant at $p < .05$ (Tables A-3, B-3, C-3, D-3)

Research Question 4

Was access to psychological and psychiatric services a significant factor in the prevalence rate of autism in each state?

In Model A, access to psychological/psychiatric services was not influential in the 1994 rate of autism; the z test statistic was 1.204 (Table A-7). There was little change in models B, C, and D (Tables B-4, C-3, and D-3).

Summary

The data were analyzed in this chapter. For the models analyzed, two of the models had goodness-of-fit statistics which were significant indicators of the robustness of the hypothesized model. Model B which had outliers removed had goodness-of-fit to the original model while Model D had a

virtually perfect fit when a path from Latino ethnicity to rate of autism in 1994 was added.

CHAPTER V

SUMMARY, DISCUSSION, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

This chapter presents a summary of the study, discusses findings for each research question, and presents conclusions and implications. Recommendations for further research conclude this chapter.

Summary

The purpose of this study was to identify variables which influenced the rate of autism in the individual states. The study examined the effects of the rate of child poverty, student ethnicity figures, access to clinically active psychological/psychiatric services, and access to autism advocacy groups on the rate of autism. The study examined if these variables were influential in the rate changes of children identified as autistic in the annual reports made to the federal government since 1990-91.

The study had 51 cases ($N = 51$); the cases were each of the 50 states and The District of Columbia. The data about each was collected from a variety of sources and a EQS structural relations data analysis program was conducted using the conceptual model that ethnicity and poverty were

major influences on rate changes in reported autism and that access to psychiatric/psychological services and autism advocacy groups were also influential in rate changes.

This research was conducted to obtain answers to these questions:

1. Was student ethnicity a significant factor in the prevalence rate of autism in each state?
2. Was the rate of child poverty a significant factor in the prevalence rate of autism in each state?
3. Was access to autism advocacy groups a significant factor in the prevalence rate of autism in each state?
4. Was access to psychological and psychiatric services a significant factor in the prevalence rate of autism in each state?

Ethnicity in the form of Latino population was the best predictor of autism rate changes in this set of conceptual models. Literally as the 1990 proportion of Latino children rose so did the 1994 rate of autism in the state.

Poverty and access to psychological/psychiatric services were not predictors of rate changes in autism in any of the models tested. Access to autism advocacy groups was a good predictor of autism rate in 1994 as well although did not impact the initial reporting rate in 1991-92.

Model D had a perfect goodness-of-fit and thus was the truest representation of the data. Model B was the most

accurate representation of the hypothesized model and has good goodness-of-fit.

Discussion

The growth rate of autism in the disability categories reported to IDEA is phenomenal; no other disability category is growing as rapidly (Kosleski, 1996). Unlike traumatic brain injury, the other disability category recently added, autism is clearly a "judgment" disability and thus, may be prone to some of the failings in labeling as have the other judgment categories of emotional disturbance, mental retardation, and learning disabilities. This study implied that the forces that influence the other "judgment" categories may be suspected in the identification rate of autism. Experts have recommended that sophisticated data bases be established to monitor the impact of societal forces on disability categories. The goodness-of-fit of Models D and B would certainly indicate that societal forces are influencing the rate of autism and warrant monitoring.

It is difficult to explain the path in model D; the higher the proportion of Latinos in a state the more that rate of autism is influenced positively. It seems counterintuitive that only one ethnic group would be of such power in autism rate differentials and this warrants further study. It could be that Latino children are part of the autism rate increases.

Conclusions

The model proposed has value in that societal influences can be influential in the changes of the rate of autism in the states. Poverty in this model had little predictive value nor does access to psychological/psychiatric services. Ethnicity and access to autism advocacy groups were the most significant variables in the model. Outlier analysis may also be instructive; it could be that Florida was an outlier because its population which is labeled Latino is Cuban rather than Mexican or others. It was not surprising that The District of Columbia was an outlier; it has such dichotomy in the socioeconomic status and ethnic make-up of its citizenry despite its small size.

Implications

Autism could be considered as a "judgment" disability meaning that societal and cultural influences which affect "judgment" disabilities require monitoring for possible impact (Harry, 1992a). Diagnostic assessment is convoluted by a variety of other overt and covert disabilities which complicate unequivocal labeling for many children (Wagner & Lockwood, 1994). This study illustrated that societal and cultural aspects influence the rate of autism in the states. The possibility for over- and under-diagnosis is certainly plausible.

The data made available by the states varied widely in quality and quantity. It is impossible to directly compare regions of the state or states without adequate data. Since the LISREL is dependent on data for input into the model, the strength of its analysis was dependent on the quality of the data used. The federal annual report data were used as no other data were available which could offer discrete numbers of individuals identified as autistic in each state. Many states did proffer data about prevalence but their data was derived from the data found in the annual reports. The Office of Special Education Programs noted that even in reporting to the federal government, states are unreliable data collectors and the data is highly suspect (Brown, 1996, personal communication).

The LISREL statistical analysis itself hindered the study. Analyzing the states using this methodology homogenized the differences between states. Ethnicity variables such as Asian Pacific Islander and Native American became insignificant in proportionality. Another form of analysis may well have been able to test this hypothesis more aptly.

Poverty was surprisingly the quiet variable in this model. It may be that poverty is centralized to areas within states and the dispersal of the data over the states diluted its influence.

Use of the statistical technique known as LISREL is not common in education. It is powerful analysis which not only can test theory but may be quite useful in theory development. Considering the large amounts of data collected by educators, particularly special educators, this technique could be instructive to the field particularly when large sample sizes are available.

Recommendations

The following recommendations for further research are proposed as a result of this study:

1. The state of Oregon has the highest rate of autism in the U.S. It would be instructive to study the demographic characteristics of that state and analyze if those factors could be predictive in autism rate changes in other states.

2. Harry's idea of "cultural capital" (1992a) should be analyzed. It could be that states that have positive cultural capital, for example, states which are characterized by high per capita income, higher than average education, low joblessness, and so forth, may be more likely to ascribe the disability label of autism due to higher awareness, educational system savvy, or the view of autism as a Cadillac disability with concomitant service provisions.

3. The perfect fit of Model D when all the states and The District of Columbia were included indicated that there may be further investigation warranted about the unique

characteristics of the Latino population and the rate of autism. Study and analysis of specific areas of the country where large populations of Latinos reside might be instructive.

4. This study should be replicated using individual state data and studying within state differences when such discrete data are available. This would create a larger N and make the findings more representative of the state.

5. An important variable omitted in this study is regional access to specialized autism clinics or treatment centers. Replication of this study with that addition might be instructive.

6. Another variable which could be studied as instructive to the model would be per pupil spending by state.

7. Since traumatic brain injury (TBI) also has been recently added to IDEA disability categories, it might be an interesting study of parallels and divergences in identification rates of TBI and autism.

8. A non-parametric rank order comparison of the states could perhaps be conducted using this data. Skew and kurtosis would be minimized and there would be no removal of any of the variables due to proportionality in the population.

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APPENDIX

TABLE A-1

CORRELATION STATISTICS

VARIABLE	BLKPROP	HISPROP	ASA	PSYCH	RATE94	POV
BLKPROP	1.000					
HISPROP	-0.197	1.000				
AUT SOC	0.056	0.228	1.000			
PSYCH	0.442	0.196	-0.011	1.000		
RATE 94	0.056	0.397	0.405	0.123	1.000	
POVERTY	0.469	0.084	-0.026	-0.089	0.082	1.000
RATE92	0.143	-0.150	-0.058	-0.089	0.215	-0.072

TABLE A-2

VARIABLE NUMBERING/LABELING

In the LISREL models, the following are the numbers and labels used to designate the variables:

V1 Variable 1 African American proportionality, BLKPROP

V2 Variable 2 Latino proportionality, HISPROP

V3 Variable 3 Autism Society of America Membership, ASA

V4 Variable 4 Access to psychologist/psychiatrist, PSYCH

V5 Variable 5 Autism rate 1993-94, RATE94

V6 Variable 6 Child poverty rate, POVERTY

V7 Variable 7 Autism rate 1991-92, RATE92

TABLE A-3

MEASUREMENT EQUATIONS WITH STANDARD ERRORS AND TEST STATISTICS

ASA =V3 =	1310.579*V1	+	4874.656*V2	+	-15.768*V6
	1490.276		2730.419		38.084
	.879		1.785		-.414
	-.442*V7	+	1.000E3		
	1.384				
	-.320				
PSYCH =V4 =	113.451*V1	+	111.379*V2	+	-1.895*V6
	18.037		33.046		.461
	6.290**		3.370**		-4.110**
	-.029*V7	+	1.00E4		
	.017				
	-1.711				
RATE94 =V5 =	.161*V3	+	3.571*V4	+	.955*V7
	.048		2.967		.467
	3.390**		1.204		2.043**
	1.000E3				

** $p < .05$

TABLE A-4

UNIVARIATE STATISTICS

VARIABLE	BLKPROP	HISPROP	ASA	PSYCH	
Mean	0.1288	0.0613	591.8431	28.4647	
Skewness (G1)	2.1674	1.9348	5.5306	3.9013	
Kurtosis (G2)	6.1859	3.4217	33.0115	19.0648	
VARIABLE	POVERTY	RATE92	RATE94		
Mean	17.5471	63.4902	363.5294		
Skewness (G1)	0.8418	3.0080	2.1172		
Kurtosis (G2)	0.3127	10.0556	4.0446		
CASE NUMBERS WITH LARGEST CONTRIBUTIONS TO NORMALIZED KURTOSIS:					
CASE NUMBER	9	10	32	33	34
ESTIMATE	516.8646	650.5780	149.1399	81.6629	160.1757

TABLE A-5

LARGEST STANDARDIZED RESIDUALS

V 5,V 2 0.310***	V 4,V 3 -0.134	V 6,V 5 0.102	V 5,V 1 -0.070	V 5,V 4 -0.056
V 5,V 3 -0.020	V 5,V 5 -0.017	V 3,V 1 0.000	V 4,V 2 0.000	V 3,V 3 0.000
V 7,V 3 0.000	V 4,V 4 0.000	V 7,V 5 0.000	V 7,V 4 0.000	V 2,V 1 0.000
V 6,V 2 0.000	V 6,V 4 0.000	V 6,V 6 0.000	V 6,V 1 0.000	V 4,V 1 0.000

*** Latino variable

TABLE A-6

GOODNESS OF FIT SUMMARY

$$\chi^2 (4, 51) = 9.964$$

	FIT INDEX	
Bentler-Bonett Normed	Fit Index=	0.873
Bentler-Bonett Nonnormed	Fit Index=	0.456
Comparative Fit Index (CFI)	=	0.896
Bollen (IFI)	Fit Index=	0.920
McDonald (MFI)	Fit Index=	0.943
Lisrel GFI	Fit Index=	0.950
Lisrel AGFI	Fit Index=	0.648

Table A-7

Standardized Solution: Partial correlations/ partial regression coefficients

ASA	=V3	=	.143 * V1 +	.255 * V2 +	-.066 * V6
R ² = .07			-.045 * V7 +	.966 E3	
PSYCH	=V4	=	.771 * V1 +	.362 * V2 +	-.493 * V6
R ² = .47			-.181 * V7 +	.727 E4	
RATE94	=V5	=	.417 * V3 +	.149 * V4 +	.251 * V7
R ² = .26			.863 E5		

TABLE A-8

MEASUREMENT EQUATIONS WITH STANDARD ERRORS AND TEST STATISTICS

ASA =V3 =	1310.579*V1	+	4874.656*V2	+	-15.768*V6
	1490.276		2730.419		38.084
	.879		1.785		-.414
	-.442 * V7	+	1.000 E3		
	1.384				
	-.320				
PSYCH=V4 =	113.451*V1	+	111.379*V2	+	-1.895*V6
	18.037		33.046		.461
	6.290**		3.370**		-4.110**
	-.029 * V7	+	1.000 E4		
	-1.711				
RATE94 =V =	.132*V3	+	2.018*V4	+	2537.291*V2
	.045		2.787		878.371
	2.923**		.724		2.889**
	1.112*V7	+	1.000 E5		
	.437				
	2.547**				

** p < .05

TABLE B-1

STANDARDIZED SOLUTION: PARTIAL CORRELATIONS/PARTIAL REGRESSION
COEFFICIENTS

ASA	=V3	=	.277 * V1	+	.400 * V2	+	-.140 * V6
R2 = .16			-.016 * V7	+	.919 E3		
PSYCH	=V4	=	.247 * V1	+	.468 * V2	+	-.602 * V6
R2=.41			-.093 * V7	+	.771 E4		
RATE94	=V5	=	.657 * V3	+	.163* V4	+	.236 * V7
R2=.54			.675 E5				

TABLE B-2

UNIVARIATE STATISTICS

VARIABLE	BLKPROP	HISPROP	ASA	PSYCH
Mean	0.1144	0.0603	426.6531	26.1122
Skewness (G1)	1.1966	1.9697	1.7751	1.3195
Kurtosis (G2)	6.034	3.4497	3.1304	1.4638
VARIABLE	POVERTY	RATE92	RATE94	
Mean	17.3612	66.0816	358.7755	
Skewness (G1)	0.9204	2.9363	2.1822	
Kurtosis (G2)	0.5000	9.5483	4.2554	

TABLE B-3

GOODNESS OF FIT SUMMARY

$$\chi^2 (4, 49) = 8.640$$

	FIT INDEX	
Bentler-Bonett Normed	Fit Index=	0.916
Bentler-Bonett Nonnormed	Fit Index=	0.702
Comparative Fit Index (CFI)	=	0.943
Bollen (IFI)	Fit Index=	0.953
McDonald (MFI)	Fit Index=	0.954
Lisrel GFI	Fit Index=	0.954
Lisrel AGFI	Fit Index=	0.678

TABLE B-4

MEASUREMENT EQUATIONS WITH STANDARD ERRORS AND TEST STATISTICS

ASA =V3 =	1244.996*V1	+	2904.187*V2	+	-12.899*V6
	736.980		1025.275		14.290
	1.689		2.833**		-.903
	-.061 * V7	+	1.000 E3		
	.522				
	-.116				
PSYCH =V4 =	27.332*V1	+	83.809*V2	+	-1.368*V6
	15.247		21.211		.296
	1.793		3.951		-4.627**
	-.009 * V7	+	1.000 E4		
	.011				
	-.792				
RATE94 =V5 =	.647 * V3	+	6.529*V4	+	.868*V7
	.097		3.951		.359
	6.651**		1.653		2.419**
	1.000 E5				

** p < .05

Table C-1

Standardized Solution: Partial correlations/ partial regression coefficients

ASA	=V3	=	.277 * V1 +	.400 * V2 +	-.140 * V6
			-.016 * V7 +	.919 E3	
PSYCH	=V4	=	.247 * V1 +	.468 * V2 +	-.602 * V6
			-.093 * V7 +	.771 E4	
RATE94	=V5	=	.608 * V3 +	.107 * V4 +	.195 * V7
R ² =.58			.259 * V7 +	.674 E5	

TABLE C-2

GOODNESS OF FIT SUMMARY

$$\chi^2 (3,49) = 5.256$$

		FIT INDEX
Bentler-Bonett Normed	Fit Index=	0.949
Bentler-Bonett Nonnormed	Fit Index=	0.807
Comparative Fit Index (CFI)	=	0.972
Bollen (IFI)	Fit Index=	0.977
McDonald (MFI)	Fit Index=	0.977
Lisrel GFI	Fit Index=	0.971
Lisrel AGFI	Fit Index=	0.727

TABLE C-3

MEASUREMENT EQUATIONS WITH STANDARD ERRORS AND TEST STATISTICS

ASA =V3 =	1244.996*V1	+	2904.187*V2	+	-12.899*V6
	736.990		1025.275		14.290
	1.689		2.833**		-.903
	-.061*V7	+	1.000 E3		
	.522				
	-.116				
PSYCH =V4 =	27.332*V1	+	83.809*V2	+	-1.368*V6
	15.247		21.211		.296
	1.793		3.951**		-4.627**
	-.009*V7	+	1.000 E4		
	.011				
	-.792				
RATE94 =V5 =	.603*V3	+	4.284*V4	+	1403.153*V2
	.098		4.042		760.241
	6.148**		1.060		1.846
	.960*V7	+	1.000 ES		
	.350				
	2.743**				

** $p < .05$

TABLE C-4

STANDARDIZED SOLUTION: PARTIAL CORRELATIONS/PARTIAL REGRESSION
COEFFICIENTS

ASA	=V3	=	.277 * V1 +	.400 * V2 +	-.140 * V6
			-.016 * V7 +	.919 E3	
PSYCH	=V4	=	.247 * V1 +	.468 * V2 +	-.602 * V6
			-.093 * V7 +	.771 E4	
RATE94	=V5	=	.608 * V3 +	.107 * V4 +	.195 * V7
R2=.58			.259 * V7 +	.674 E5	

TABLE D-1

STANDARDIZED SOLUTION: PARTIAL CORRELATIONS/PARTIAL REGRESSION
COEFFICIENTS

ASA	=V3	=	.143 * V1 +	.255 * V2	+	-.066 * V6
			-.045 * V7 +	.966 E3		
PSYCH	=V4	=	.771 * V1 +	.362 * V2	+	-.493 * V6
			-.181 * V7 +	.727 E4		
RATE94	=V5	=	.342 * V3 +	.084 * V4	+	.345 * V2
R ² =.36			.293 * V7 +	.803 E5		

Table D-2

Goodness of Fit Summary

$$\chi^2 (2, 51) = 2.326$$

	FIT INDEX	
Bentler-Bonett Normed	Fit Index=	0.970
Bentler-Bonett Nonnormed	Fit Index=	1.082
Comparative Fit Index (CFI)	=	1.000
Bollen (IFI)	Fit Index=	1.009
McDonald (MFI)	Fit Index=	1.007
Lisrel GFI	Fit Index=	0.987
Lisrel AGFI	Fit Index=	0.880

TABLE D-3

MEASUREMENT EQUATIONS WITH STANDARD ERRORS AND TEST STATISTICS

ASA =V3 =	1310.579*V1	+	4874.656*V2	+	-15.768*V6
	1490.276		2730.419		38.084
	.879		1.785		-.414
	-.442*V7	+	1.000 E3		
	1.384				
	-.320				
PSYCH=V4 =	113.451*V1	+	111.379*V2	+	-1.895*V6
	18.037		33.046		.461
	6.290**		3.370**		-4.110**
	-.029*V7	+	1.000 E4		
	-1.711				
RATE94 =V5 =	.132*V3	+	2.018*V4	+	2537.291*V2
	.045		2.787		878.371
	2.923**		.724		2.889**
			1.112*V7	+	1.000 E5
	.437				
	2.547**				

** indicates $p < .05$

Table D-4

WALD TEST FOR DROPPING PARAMETERS

STEP	PARAMETER	CHI-SQUARE	D.F	PROBABILITY
1	V3, V7	0.102	1	0.749
2	V3, V6	0.242	2	0.886
3	V7, V6	0.919	3	0.919

Table E-1

Data used in Variable Derivation

The following data were used in variable derivation:

State (coded numerically by alphabet)

1991-92 number of autistic individuals reported to IDEA

1992-93 number of autistic individuals reported to IDEA

1993-94 number of autistic individuals reported to IDEA

1991-92 elementary and secondary school enrollment in
public schools

1992-93 elementary and secondary school enrollment in
public schools

1993-94 elementary and secondary school enrollment in
public schools

1990 rate of all children under age 18 living in poverty

1990 rate of White children under 18 living in poverty

1990 rate of African American children under 18 living
in poverty

1990 rate of Latino children under 18 living in poverty

1990 rate of Native American children under 18 living in
poverty

1990 rate of Asian/Pacific Islander children under age
18 living in poverty

1990 rate of other ethnicities under age 18 living in
poverty

1990 number of White children under 18

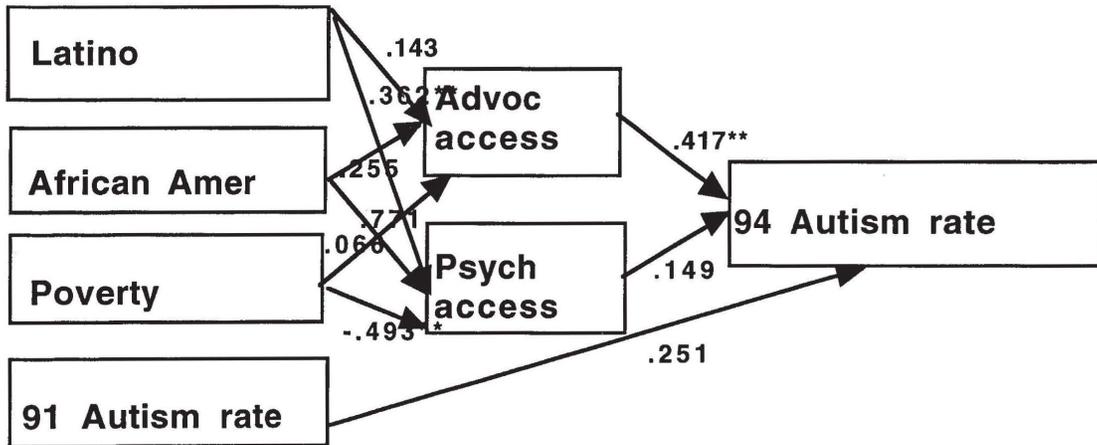
1990 number of African American children under 18

- 1990 number of Latino children under 18
- 1990 number of Native American children under 18
- 1990 number of Asian/Pacific Islander children under 18
- 1990 number of other ethnicity children under 18
- 1992 number of members of Autism Society of America
(state or national membership)
- 1990 rate per 100,000 population of clinically active
psychologists/psychiatrists

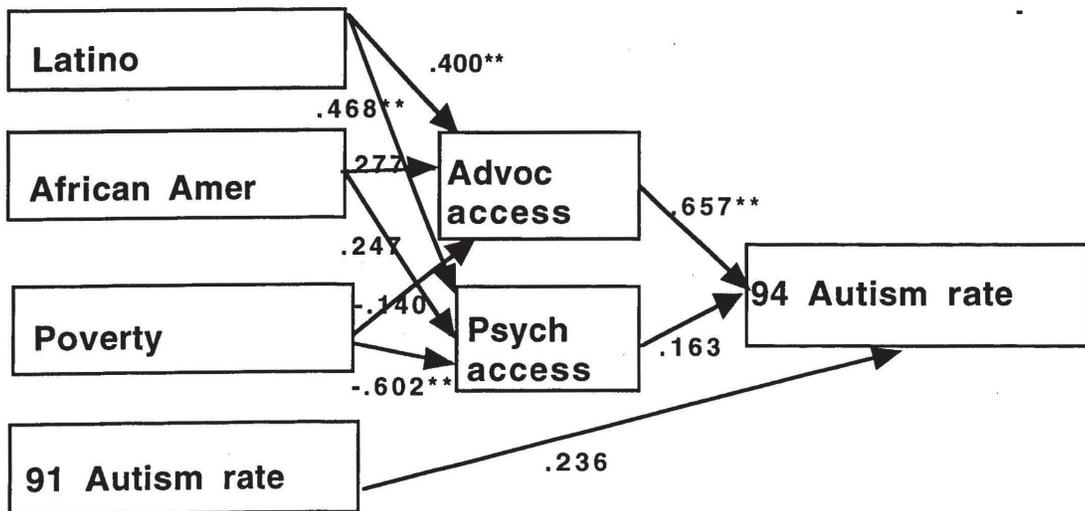
Table E-2

Models with Regression Coefficients

Model A



Model B

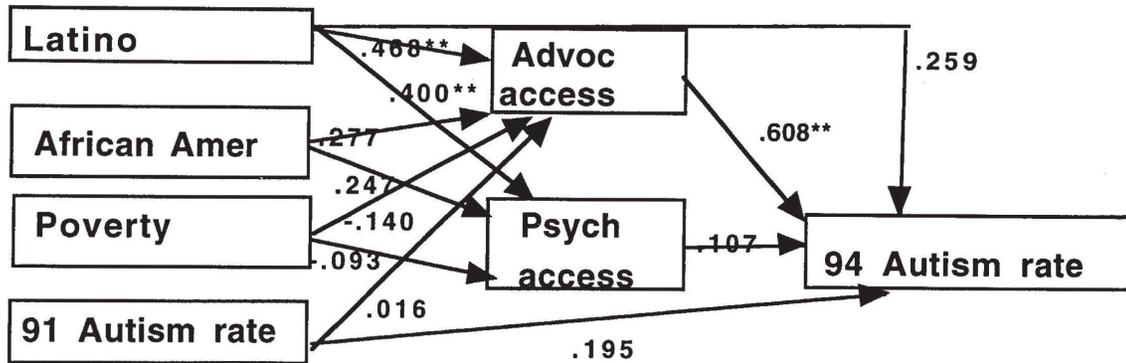


** indicate significant path coefficient

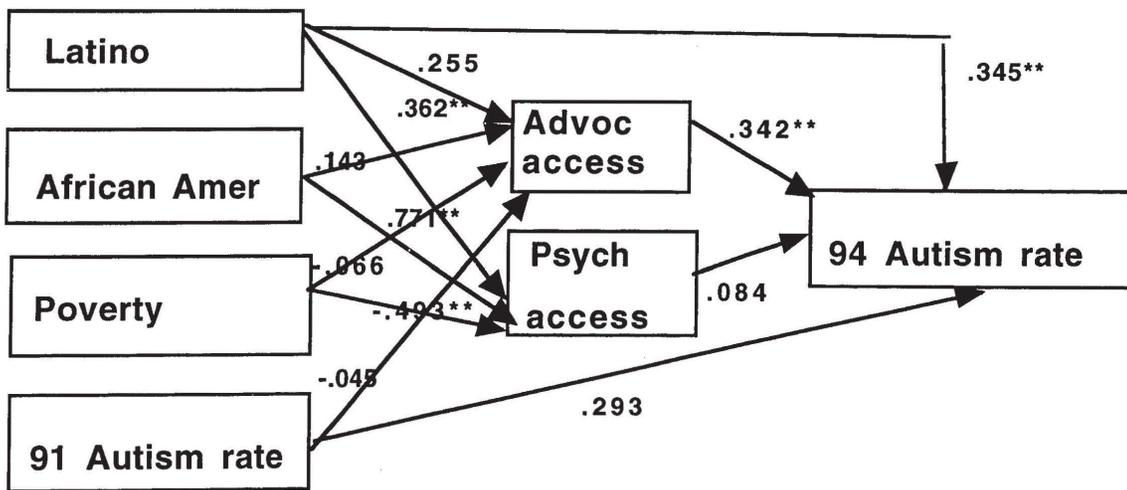
Table E-2

Models with Regression Coefficients

Model C



Model D



** indicate significant path coefficient