

EPIDEMIOLOGIC AUTISM FOLLOW-UP STUDY USING THE
UTAH POPULATION DATABASE

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ABSTRACT

Few epidemiologic studies have examined outcome of autism in adulthood. This study followed up a population-based sample of adults for several outcome measures through use of the Utah Population Database (UPDB). Youth originally assessed with DSM-III criteria as having autism ($N=222$) or not having autism ($N=94$) in the UCLA-University of Utah Epidemiologic Survey of Autism were examined. All youth were originally targeted because they were suspected of having autism or had developmental delays. Names of these individuals were submitted to the UPDB to link to driver's license, identification card, marriage, divorce, and offspring records. Comparisons were also made to the general population when these were available.

Computer records were found for 185 of the autism and 84 of the not autism subjects from the initial survey. The autism group had a smaller proportion married (3.8%), with driver's licenses (16.8%), and with children (2.2%); however, there were more people with identification cards (54.1%). One individual in each group was divorced. No significant differences were found between groups in number of linked records, $\chi^2(1, N= 316) = 1.9, p > .05$, those deceased, $\chi^2(1, N = 269) = 1.57, p > .05$, or divorced, $\chi^2(1, N= 269) = 0.036, p > .05$. Significant differences existed between groups for driver's license, $\chi^2(1, N= 269) = 11.8, p < 0.001$, identification card, $\chi^2(1, N= 269) = 12.3, p < 0.001$, marriage, $\chi^2(1, N= 269) = 11.4, p < 0.001$, and offspring, $\chi^2(1, N= 269)$

= 4.2, $p < 0.05$. Both groups exhibited excess mortality in relation to the general population. Factors related to outcome are discussed.

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CHAPTER I

INTRODUCTION

Autistic Disorder is a neurodevelopmental disorder first assessed in early childhood. It is characterized by difficulties in social interaction, abnormal communication, and the presence of restricted or unusual patterns of behavior. These are commonly referred to as the triad of impairments. Although the causes of autism are currently unknown, the etiology is most likely a result of underlying genetic factors being influenced by environmental triggers. Heterogeneous in nature, Autistic Disorder manifests itself differently in individuals. It is often viewed as a spectrum disorder, in that autistic symptoms occur on a continuum ranging from mild to severe. This means that there may be an individual on one end of the spectrum who is of average or above average in intelligence, yet has some social idiosyncrasies and deficits in communication, while another individual on the other end of the spectrum may be nonverbal, intellectually disabled, socially withdrawn, and possess debilitating behaviors. Spectrum applies in another sense: Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder- Not Otherwise Specified are often grouped together into a category called Autism Spectrum Disorders. Although some individuals with autism exhibit an abatement of autistic symptoms over time, it is most accurately perceived as a lifelong disorder.

Numerous aspects of autism are currently under investigation, such as those studies targeting the etiology, genetics, brain functioning, early identification, and treatment efficacy of various interventions. However, there is limited research addressing the outcome of adults with autism and how those diagnosed with autism in childhood fare over time. The few studies that have been conducted show that adult outcome is poor for the vast majority of individuals, although a small proportion show loss of autistic symptoms and/or no longer meet diagnostic criteria for autism.

This study proposes to examine specific measures of outcome in an epidemiologic sample of adults with autism. Measures of outcome will include rates for mortality, license obtainment, marriage and divorce, and presence of offspring. The adults in this study were first diagnosed with autism during the mid to late 1980s and were followed up over 20 years later.

Autistic Disorder

One of the first people to describe autism was Leo Kanner. While working at Johns Hopkins University, Kanner (1943) studied a select group of individuals who were socially withdrawn, fixated, exhibited oddities in their verbal forms of communication, and insisted on predictability in routine. Since Kanner's early depictions, the key features of autism have been more comprehensively illustrated. The core characteristics, requirements for diagnosis, associated features, and prevalence rates of those with autism will be presented below.

Characteristics

The characteristics of Autistic Disorder are outlined in the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition-Text Revision (DSM-IV-TR, American Psychiatric Association, 2000). Autistic Disorder is one of the five sub-categories under the overall umbrella of the Pervasive Developmental Disorders. It is differentiated from Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified. According to the DSM-IV-TR (2000), individuals meeting criteria for Autistic Disorder must have severe and pervasive impairments in three areas of development: social relatedness, communication, and interests and behavior.

Individuals with Autistic Disorder exhibit difficulty interacting with others in a social manner (DSM-IV-TR, 2000). These social difficulties may include the inability to use or understand nonverbal types of communication, such as eye contact, facial expression, or body language. For example, a person with autism may not be able to tell when a conversation is ending, when they are talking too much, or be able to decipher how close to stand to another person during a conversation. During social interactions, eye contact may be very intense with no breaks, nonexistent or fleeting, or unusual. Forming appropriate relationships, such as friendships or intimate partnerships, may be challenging. Individuals may also have problems sharing their interests with others appropriately, or may lack the desire to communicate achievements or other topics they find exciting. Often times, individuals with autism also lack social or emotional reciprocity, meaning they have difficulty providing comfort when others are upset or hurt or are unable to be empathetic in times where this is warranted.

Along with difficulties in social relatedness, individuals meeting criteria for Autistic Disorder also display qualitative impairments in communication (DSM-IV-TR, 2000). Speech development may be delayed or there may be a complete lack of verbal communicative language altogether. Individuals with autism may have problems with reciprocal conversations, such as sustaining a conversation, engaging in “small talk” purely for the social means of interacting with another person, or introducing topics of conversation unrelated to their own interests. Oftentimes, in verbal individuals, unusual language is present. This could include stereotyped or repetitive language such as immediate or delayed echolalia and/or verbal rituals, or idiosyncratic language that is excessively formal or contains neologisms. Difficulty with developmentally appropriate spontaneous imaginary or imitative social play is another characteristic of Autistic Disorder.

The third category within the triad of impairments, as defined in the DSM-IV-TR (2000), is restricted or repetitive interests or behaviors. An individual with an Autistic Disorder may have one or more circumscribed interests or preoccupations dependent on their respective developmental age. For example, a child with autism may be consumed with dinosaurs in a way that is more intense than their peers and which also interferes with social functioning. Exhibiting repetitive hand or body movements, such as hand flapping or rocking, constitutes another difficulty. An individual may become upset with minor changes in his or her routine or within the immediate environment, or insist on completion of nonessential rituals. Lastly, individuals meeting criteria for an Autistic Disorder may either be overly drawn by sensory activities or find them aversive, or may be more interested in parts of objects in contrast to the whole object.

Diagnosis

The American Psychiatric Association did not have criteria separating autism from other disorders, such as psychosis or childhood schizophrenia, until 1980. It was at that time that a systematic way of characterizing Autistic Disorder first emerged in the Diagnostic and Statistical Manual of Mental Disorders-Third Edition (DSM-III, American Psychiatric Association, 1980). The criteria distinguishing autism have evolved through the various revisions of the Diagnostic and Statistical Manual of Mental Disorders (DSM). For example, because the criteria that were outlined in the DSM-III were viewed as being too inclusive, requirements were expanded upon in the subsequent revision (Petersen, Kube, & Palmer, 1998). Most researchers and clinicians in the United States currently use the DSM-IV-TR to assess autism and the other pervasive developmental disorders.

In order to meet criteria for an Autistic Disorder, an individual must exhibit six or more of the impairments listed in the DSM-IV-TR, including at least two in the social interaction domain and at least one each in the communication and restricted interest domains. There must also be a delay in social interaction, socially communicative language, or symbolic play by the time the child is 3 years old. These delays cannot be better explained by the individual meeting criteria for Rett's Disorder or Childhood Disintegrative Disorder (DSM-IV-TR, 2000).

Associated Features

There are several associated features that go along with a diagnosis of Autistic Disorder. A disproportionate gender distribution exists, with males much more likely to meet diagnostic criteria in comparison to females. According to the DSM-IV-TR (2000), rates of males with autism are four to five times higher than females. Other research (Fombonne, 1999, 2003b, 2005) has shown male to female ratios ranging from 3.8:1 to 4.3:1, which are commensurate with the DSM-IV-TR estimate. Even though there are fewer females with autism than males, females are more apt to have lower cognitive abilities (DSM-IV-TR, 2000). In fact, a significant number of individuals with autism also have a diagnosis of mental retardation, although the degree to which this correlates with the disorder varies. Based on epidemiologic data (Fombonne, 1999, 2003b), it is projected that between 70-80% of individuals with autism also have mild to severe intellectual impairments.

In addition to mental retardation, there are also several other conditions associated in both adults and children with autism. Elevated rates of fragile X syndrome and tuberous sclerosis have been reported (DSM-IV-TR, 2000; Fombonne, 2003b, 2005; Kielinen, Rantala, Timonen, Linna & Moilanen, 2004). Other research has found increased rates of epilepsy, Down's syndrome, cerebral palsy, and other genetic disorders (Danielsson, Gillberg, Billstedt, Gillberg & Olsson, 2005; Kielinen et al., 2004).

Behavioral and psychological difficulties may also be present in individuals with autism. For example, Lainhart and Folstein (1994) concluded that 35% of the cases they reviewed had an affective disorder. Additionally, depression, anxiety, obsessive-compulsive characteristics, hyperactivity, inattentiveness, tics and Tourette's disorder,

schizophrenia, aggressiveness, self-injurious behavior, disruptions in sleep, and abnormal eating behaviors have also been described in those with an Autistic Disorder (DSM-IV-TR, 2000; Lainhart, 1999; Lefeyer et al., 2005; Polimeni, Richdale & Francis, 2005). These comorbidities occur in varying rates. Howlin (2002) noted that despite the lack of large and representative studies documenting rates of anxiety and affective disorders in individuals with autism, many adults struggle with these types of difficulties. Ethnicity, immigrant status, and social class were not found to be correlated with rates of autism (Fombonne, 2003b, 2005).

Prevalence

Along with understanding the key features associated with Autistic Disorder, assessing prevalence rates of those with autism within the general population is also important. Tracking rates over time permits accurately ascertaining how many individuals possess the disorder. Autistic Disorder used to be considered rare. In the mid to late 1980s, an American team (Ritvo et al., 1989) conducted an epidemiologic survey reporting autism prevalence estimates to be 4 per 10,000 in the general population. Other figures cited prevalence rates to be 2-20 per 10,000 individuals (DSM-IV-TR, 2000) and a review of 16 published surveys between 1966 and 1991 in various countries showed a median rate of 4.4 per 10,000 individuals (Fombonne, 2003b).

However, more recent assessments of prevalence show increasing rates. For example, Fombonne (2005) found that current rates for autistic disorder, pervasive developmental disorder, and all spectrum disorders combined were 13 per 10,000, 21 per 10,000 and 60 per 10,000, respectively. Some authors (Fombonne, 2003b, 2005;

Gernsbacher, Dawson, & Goldsmith, 2005; Grinker, 2007; Kielinen, Linna, & Moilanen, 2000; Wing & Potter, 2002) postulate that changing diagnostic criteria and study designs, earlier and better identification, and increased public awareness influences elevations in prevalence estimates over time.

Outcome Literature

It is essential to understand what happens to children with autism when they grow up. Longitudinal prognosis can be meaningful on a variety of levels. It helps to delineate individual expectations for adult quality of life, address parental concerns of long-term providence and acceptance by others, as well as to theoretically explore the economic and societal implications of integrating and taking care of these individuals into adulthood. Additionally, by examining adults with autism, we can more comprehensively understand the outcome of these individuals in intellectual, social, adaptive, daily living, and communicative domains. Since many individuals with autism also have intellectual impairments, the literature addressing the outcome of adults with intellectual disabilities is reviewed first.

Prior research has shown that a deficit in social relatedness is one of the best predictors of challenges in later functioning for those with intellectual disabilities (Beadle-Brown et al., 2002; Beadle-Brown, Murphy, & Wing, 2005). For instance, a cohort of individuals with severe intellectual disabilities (including many with autism) from the Camberwell district in London were prospectively followed up after a period of 25 years by Beadle-Brown et al. (2005). Almost 100 participants, aged 27 through 41, were assessed using a variety of instruments including the Lifestyle Satisfaction Scale,

Schedule of Handicaps Behaviors and Skills, Adaptive Behavior Scales, Quality of Life Questionnaire, and language and intelligence tests. Over half of the sample was rated as having poor outcome, 43% of the participants had fair outcome, and a mere 3% of the sample had good outcome. The researchers' statistical regression analyses demonstrated that those in the original sample with the worst social impairment had the poorest outcome at follow-up, while higher intelligence and fewer challenging behaviors at baseline were predictors of better outcome.

Other researchers have found similar results when examining outcome in those faced with limited intellectual functioning, although these results vary depending on the degree of impairment (Hall et al., 2005). Samples taken from the National Survey of Health and Development database, comprised of individuals with both mild and severe intellectual impairment, were compared to each other as well as to those with normal intellectual functioning on measures of social outcome. The mildly intellectually impaired individuals were more likely to obtain jobs, get married, have children, own a home, or be involved in higher education than were those in the severely impaired group, but less so than were individuals of average intelligence.

Related to the overarching conceptualization of adult outcome for those with intellectual disabilities is the research explicitly honing in on the outcome of individuals with autism. Early outcome, longitudinal, population-based, and review studies for adults with autism will be outlined below.

Early Outcome Studies

The first outcome studies related to autism emerged in the late 1950's. These were primarily descriptive in nature and many had substantial methodological flaws such as varying selection criteria for diagnostic inclusion and a wide array of heterogeneity in the age and intellectual ability of study participants (Creak, 1963; Lotter, 1978). During this time, Eisenberg (1956) reported on a sample of 63 individuals, mainly adolescents, who were categorized as largely dependent on the support of others. However, one-third of his subjects made moderate social gains. Although a small proportion of the individuals in Eisenberg's sample with the best outcomes still faced problems with social functioning, he described them as acquiring a high level of independence. He posited that autism is a "disturbance in social perception" and that there were many feasible outcomes for those with the disorder. Those studies containing more clearly defined subjects with autism did not arise until several decades later.

Kanner (1971) followed up 11 subjects originally reported as having autism in 1943. His sample included 1 woman and 10 men. These individuals were reevaluated as adults, when they were in their 20s and 30s. This publication provided detailed life histories of these cases. The subjects he reported on were not representative of his larger sample, in that they were higher functioning and were able to achieve some degree of independence. These included examples such as being able to acquire a college degree, becoming employed, owning a home, and getting married.

Michael Rutter and his colleagues conducted the first empirically driven and systematically based prospective studies in the late 1960s and early 1970s (Lockyear & Rutter, 1969, 1970; Rutter, Greenfield, & Lockyer, 1967; Rutter & Lockyear, 1967). The

results showed that over 60% of the individuals studied obtained poor social outcomes. Most adults resided with their families, in residential treatment facilities, or long-term hospital care. Few had jobs or friendships, and the vast majority remained largely dependent on the support of others. Although many individuals made improvements over time, overall outcome was dismal in most of the reports. In more recent years, autism researchers have attempted to implement more rigorous standards in assessing outcome, although these explorations are still far from perfect.

Longitudinal Studies

The vast majority of published studies examining the long-term course for adults with autism are prospective, rather than retrospective. These studies suggest fairly poor prognosis for adults with autism despite their differences in methodology and the heterogeneity of samples utilized (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996; Beadle-Brown et al., 2002; Howlin, Goode, Hutton, & Rutter, 2004; Howlin, Mawhood, & Rutter, 2000; Kobayashi, Murata, & Yoshinaga, 1992; Larsen & Mouridsen, 1997; Mawhood, Howlin, & Rutter, 2000; Rumsey, Rapoport, & Sceery, 1985; Stein et al., 2001; Venter, Lord, & Schopler, 1992). Most of the research with this prospective type of design has been conducted with small clinical samples of individuals first assessed in childhood. These studies have examined samples of adults with autism all across the world.

Prospective Studies

In one of the largest follow-up studies to date, 201 children with autism in Japan who participated in therapeutic camps and specialized clinics were followed up as adults (Kobayashi et al., 1992). They were surveyed through questionnaires and both phone and in-person interviews. Staff consultations and the examination of prior intelligence quotient (IQ) scores and language levels were also made. Outcome measures demonstrated that 21.8% of the subjects were employed, the majority lived with their parents, and none were married. Acquisition of present language developmental levels conveyed the following: 16.2% of the sample was rated as being very good, 30.5% fell into the good category, 32% were fair, 9.1 % were poor, and 12.2 % were very poor. Additionally, present adaptive levels segregated the sample into the following categories: 10.7% were very good, 16.2% were good, 26.9% were fair, 22.8% were poor, and 23.4% were very poor. Speech at 6 years for males and childhood IQ for both genders was related to better outcome.

Another outcome study (Ballaban-Gil et al., 1996) showed that the majority of the subjects with autism followed, including 54 adolescents and 45 adults, experienced significant difficulties. At follow-up, subjects' cognitive functioning varied, with approximately a third of the sample falling into each of the three categories: near or near normal intelligence, mild mental retardation, and severe mental retardation. Of those studied, 69% had behavioral problems, 35% of the teens and 49% of the adults exhibited self-injurious behavior, 50% had stereotypic behaviors, and more than 90% had social deficits. Additionally, only 35% of the group had normal language fluency and 29% had normal comprehension of oral language. Almost a third of the total sample and over half

of the adults were living in residential placements. A mere 11% of the adults were employed in menial jobs and 16% of the adults were employed in sheltered workshops.

In the late 1990s, Danish researchers (Larsen & Mouridsen, 1997) followed up nine individuals with autism and nine individuals with Asperger's Disorder who had been admitted as psychiatric inpatients as children. Cognitive functioning varied considerably in the sample, ranging from severe mental retardation to average intelligence. The adults were in their 30s and 40s ($M=38$) and length of follow up was 30 years. Almost 17% were independently employed and the remaining subjects were involved with sheltered workshops or day programs. In regard to outcome, 28% of the sample achieved good outcome, 28% had fair outcome, 17% had poor outcome, and 28% had very poor outcome according to criteria put forth by Lotter (1978) for overall social adjustment. The subjects with autism had poorer outcome overall, as measured by educational attainment, employment, independence, marriage, offspring, and degree of support needed.

Characteristics of autism tend to remain stable over time. Beadle-Brown et al. (2002) studied 144 children from Camberwell, London as adults. They found that their sample still met criteria for autism based on the Handicapped Behavioral Skills Schedule after 12 years of follow-up. Another study investigated a sample of severely impaired adults with autism in institutional settings who were diagnosed as children (Stein et al., 2001). Through application of outcome measures such as the Childhood Autism Rating Scale, DSM criteria, clinical interviews, and the Raven's Colored Progressive Matrices test, they determined that the diagnosis of autism remained consistent in all of the subjects they investigated. Social interaction continued to be the most problematic

domain of functioning. Most of their subjects had severe mental retardation, two-thirds of the sample had no spoken language, 75% required neuroleptic treatment, and almost half had a convulsive disorder.

Howlin et al. (2004) followed up 68 children from a clinical sample in London. These adults with autism had childhood performance intelligence quotients above 50. The outcome measures utilized included the Autism Diagnostic Interview, standardized measures of intellectual functioning, language and attainment tests, as well as occupational and educational data. Howlin found that 78% of the sample left school without any formal qualifications and two individuals were able to obtain postgraduate degrees. A third of the group was employed, although mainly in supported environments. Over half of the group reportedly had no friends, a third still lived at home, and half resided in residential placements. The majority of the sample still exhibited autistic type symptoms and 15% had epilepsy. The researchers comprised a composite outcome rating score showing that 12% of their sample had very good outcome, 10% had good outcome, 19% had fair outcome, 46% had poor outcome, and 12% exhibited very poor outcome.

Higher-Functioning Samples

In one of the earlier prospective studies (Rumsey et al., 1985), 14 males between the ages of 18 and 39 ($M = 28$) who were diagnosed with autism as children were followed up. Seven of the cases had been originally assessed by Kanner. Nine of the subjects had verbal and performance IQs above 80. Follow-up measures included diagnostic and parent interviews, cognitive and achievement instruments, and in person observations. All of the subjects continued to exhibit social, behavioral, and psychiatric

problems at follow-up. Very few were employed or described as independent, 70% showed stereotyped movements and concrete thinking, and almost half had difficulties with speech, anxiety, or affect.

Venter et al. (1992) followed 58 high functioning individuals with autism over an average of 8 years. Subjects' initial IQ scores were equal to or above 60 ($M = 80.2$, $SD = 19.3$) on nonverbal measures of intelligence. Individuals were between the ages of 10 and 37 at follow-up. There were 23 females and 35 males in the sample. Outcome was determined through use of intelligence tests, parent interviews, an adaptive measure, language and attainment tests, the Autism Diagnostic Interview, and the Autism Diagnostic Observation Schedule. Results showed that almost half of the school-aged subjects were in special education. In the adult sample, 27% were employed, 59% were in sheltered or supervised programs, and 14% were unemployed and not in school. One of the subjects over 25 years of age had completed college. None of the participants were married, two lived alone, and the rest were largely dependent on their family or others.

The cognitive, social, behavioral, psychiatric, and language outcomes for those assessed in childhood with either autism or developmental receptive language disorders were examined in two prospective studies (Mawhood et al., 2000; Howlin et al., 2000). There were 19 men in the autism group and 20 men in the language group. The groups were matched based on initial nonverbal IQ ($M = 92-93$) and expressive language. Subjects were followed for a period of approximately 16 years. Results showed that the autism group made more improvements in verbal IQ and receptive language scores; however, these scores were still significantly impaired. There were no group differences on attainment tests. Those with autism continued to exhibit more difficulties with

stereotyped behavior patterns, social relationships, employment, and independence in adulthood in comparison to the language group.

Although limited by their methodology, retrospective studies of adults with autism also shed light on prognosis of outcome over time. The two studies reviewed here include subjects with higher levels of intellectual functioning. Szatmari, Bartolucci, Bremner, Bond, and Rich (1989) assessed 16 children with autism from Toronto identified from childhood records and followed them up as adults. The mean IQ of their sample was 92, with a range of 68-110. Follow-up measures consisted of structured interviews, rating scales, measures of adaptive behavior, and intelligence and neuropsychological tests. Despite their sample being higher functioning in terms of IQ, the majority still had poor occupational and social outcomes, as well as psychiatric symptoms. However, a fourth of the total sample was rated as having a very good outcome.

Additionally, Piven, Harper, Palmer, and Arndt (1996) examined 38 high-functioning adults and adolescents between the ages of 13 and 28 who were originally diagnosed as having autism by the University of Iowa Child Psychiatry Clinic. Subjects' nonverbal IQ ranged from 67 to 136 ($M= 88.4, SD= 6.1$). The outcome measures utilized were prior IQ and medical records and the Autism Diagnostic Interview. Subjects in this study made significant improvements in social and communication areas, but still exhibited many ritualistic and repetitive types of behavior. All of the teenagers no longer met current DSM criteria for autism but still demonstrated impairments.

Population Based Studies

There are four published population-based follow-up studies that contribute to our understanding of the outcome for adults with autism. These are particularly important because they are relevant to the general population of adults with autism and findings can be generalized to more than just clinic-ascertained populations. As early as the mid 1970's, Lotter (1974a, 1974b) published a series of papers reporting on the outcome of 32 patients identified as having "autistic conditions" during a 1964 epidemiologic survey conducted in England. These subjects were between the ages of 16 and 18 at follow up. Case record review, interviews, and scores obtained from the Raven's Progressive Matrices test guided outcome classification. Overall adjustment, derived from Eisenberg (1956) and Rutter and Lockyer (1967) was divided into the following four categories (Lotter, 1974a):

Good outcome: meant that the child was leading a normal or near-normal social life and was functioning satisfactorily at school or at work.

Fair outcome: meant that the child was making social and educational progress in spite of significant, even marked, abnormalities in behavior or interpersonal relationships.

Poor outcome: meant that the child was severely handicapped and unable to lead an independent life, but there was still some measure of social adjustment and it was felt some potential for social progress remained.

Very Poor outcome: meant that the child was unable to lead any kind of independent existence. (p.15)

Lotter found that 62% of his cases experienced poor or very poor outcome. Only one individual was employed. Overall, women fared worse than the men; none of the women were rated as falling into the good or fair social adjustment categories.

Several decades later, Gillberg and Steffenburg (1987) followed up 46 subjects diagnosed during childhood with autism (through application of DSM-III criteria) or with other types of childhood psychoses. The latter group included those presenting with

disintegrative psychosis or “autistic-like” symptoms. The subjects in this study were between the ages of 16 and 23 at follow up and were initially diagnosed in the 1960s. The vast majority had some degree of mental retardation. They were assessed through means of case record reviews, structured phone interviews, clinical examinations, and adjunct interviews.

Lotter’s (1978) outcome criteria for overall social adjustment formulated their indication of outcome status. A fifth category labeled “restricted but acceptable outcome” was also added by the researchers, falling in between the “fair” and “poor” outcome domains. The results demonstrated that 59% of the sample had poor or very poor outcome and 35% developed epilepsy.

Another Swedish group (von Knorring & Hagloff, 1993), followed up 34 individuals originally assessed with Autistic Disorder during a 1977 to 1979 epidemiologic survey conducted in Västerbottens. Four individuals from the original survey refused to participate, two of whom were “well functioning employed adult young men living by themselves” (von Knorring & Hagloff, 1993, p. 92). Length of follow-up was between 8 to 9 years and the sample consisted of 20 males and 14 females. Subjects were between the ages of 10 and 29 years at follow-up. Measures of outcome included the following: the Medical Research Council's Schedule of Handicaps, Behaviours and Skills, the Diagnostic and Statistical Manual of Mental Disorders-III-Revised (DSM-III-R) criteria, Lotter's modified questionnaire, and derived educational and social information.

Although one male individual reportedly “lacked all autistic symptoms” (von Knorring & Hagloff, 1993, p. 93), most of the individuals maintained symptoms of

autism over time and were categorized as having poor outcome. However, the researchers also concluded that there were language and communication advancements in the majority of participants. The best functioning subjects were male and severe mental retardation was most pronounced in females. One case also had developed signs of schizophrenia and a few others had deteriorated in their functioning.

The more recent research addressing the outcome of epidemiologic samples have also been carried out by Swedish teams. For example, Billstedt, Gillberg, and Gillberg (2005) conducted a prospective population-based follow-up study of 120 individuals with autism from childhood to adulthood. Seventy-eight of these adults had met DSM-III-R criteria for Autistic Disorder in childhood, whereas 42 individuals exhibited “autistic-like” conditions. The subjects were between the ages of 17 and 40 ($M=25.5$) and were followed up between 13 and 22 years. They were born between 1962 and 1984. As found in the prior study (Gillberg & Steffenburg, 1987), a minority of individuals in both groups were rated as being of average intelligence: 20% of those in the autism group and 14% of those in the “autistic-like” conditions group. When originally assessed, the researchers administered the following measures to participants: the Handicaps, Behaviours, and Skills Schedule, the Childhood Autism Rating Scale, the Autism Behavior Checklist, and a full medical assessment comprised of karyotyping, neuroimaging, EEG recordings, an auditory brainstem response exam, and hearing and vision examinations. At the time of follow-up, 108 individuals participated. When reassessed, the researchers employed a diagnostic interview, various intelligence tests, an adaptive functioning measure, psychiatric medical evaluation, and the Global Assessment of Functioning (GAF) scores to evaluate current functioning.

Classification of outcome was based on Lotter's criteria, emulating the previous study. The results showed that outcome was poor for the vast majority of the subjects: none of the participants met criteria for good outcome and 78% had poor or very poor outcome. No one had a GAF score above 70. Diagnosis remained stable for those originally placed in the Autistic Disorder group. Forty-three percent had epilepsy and almost 50% had a major medical problem. The researchers concluded that outcome is subject to a more extreme prognosis than previously contended, especially for lower functioning individuals with autism initially assessed in the 1970s and 1980s.

Review Studies

Several studies have summarized the autism outcome literature (Gillberg, 1991; Nordin & Gillberg, 1998; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). These reviews have found that 60-75% of study cases show poor or very poor social adjustment, 5-15 % show good outcome, and 40-55% of subjects reside in institutions. Outcome for children with classic autism is variable, meaning a very small percentage "recover" and some do make social improvements; however, most remain severely impaired and less than 10% do very well in adult life or hold jobs. A full 60% remain dependent on others for the rest of their lives. Cognitive and behavioral deterioration is present in adolescence for a small percentage of individuals with autism.

Predictor Variables of Better Outcome

If almost two-thirds of children with autism make minimal improvements in adulthood, what can we conclude about the variables that are related to future outcome?

Most of the outcome studies mentioned previously have found that nonverbal IQ in childhood and early useful speech are powerful prognostic variables for good outcome. Howlin et al. (2004) showed that subjects with a childhood performance IQ less than 70 had worse prognosis, although there were variations in the higher IQ levels as well as individual discrepancies. All the participants in the “very good” outcome category and most in the “good” and “fair” groupings had some communicative speech by age five. Those with useful speech at age five also had significantly higher social ratings and residential status in adulthood. Worse outcome based on the Childhood Autism Rating Scale was correlated with lower IQ on the Raven’s measure in another study (Stein et al., 2001). The correlation between childhood IQ and communicative speech is not entirely understood yet, and more research needs to be conducted in this area. Kanner (1971) also hypothesized that special skills were related to better outcome.

When taken cumulatively, outcome studies increase our understanding of the lives of adults who have autism; however, they have limitations. Seltzer et al. (2004) illustrated that since Kanner first coined the term autism 60 years ago, we are only now seeing the first cohort of adults with autism in old age. Thus, the field of outcome research is still emerging. Changing diagnostic criteria, heterogeneity among subjects, usage of diverse outcome measures, and reliance on smaller clinically based samples make it challenging to accurately interpret findings (Tsatsanis, 2003). More studies, such as those examining predictor variables and encompassing subjects within the entire autism spectrum, are needed in order for us to draw valid conclusions.

Specific Indicators of Outcome

Our reviews of the outcome literature identified very few studies addressing how many adults with autism become licensed drivers, have state identification cards, marry or divorce, have children, or are deceased. The sections below elucidate each of these factors individually.

License Obtainment

Currently, there is no published research that we could find examining how many individuals with autism obtain driver's licenses or records of those who drive. Additionally, rates of state identification card attainment are unknown.

Marriage, Divorce, and Offspring

Investigating how many adults with autism marry, divorce, and have children are also areas receiving little attention in prior adult outcome studies. In her review of 16 follow-up studies, Howlin (2004) found the following: 6% of all individuals followed were reportedly married, two studies mentioned individuals having children, and there were only minimal accounts of adults being divorced. In our review, Kanner (1971) reported on a married male who had a child. There was a married participant in a high-functioning sample of adults with autism (Szatmari et al., 1989). Four adults with Asperger's Disorder in another study were married, two of whom later divorced (Larsen & Mouridsen, 1997). The male and female who remained married in this sample both have children, four and two, respectively. Three men meeting criteria for either Autistic Disorder or Asperger's Disorder were married or living with a partner; one had a child

according to Howlin (2003). One woman with Asperger's Disorder was also divorced in this same sample. Another study conducted by Howlin et al. (2004) reported on three men who were married, one of whom later divorced.

Mortality

Mortality is another facet of autism that has only been mentioned briefly in the follow-up literature. Mortality rates are generally given as part of the overall picture of outcome (Ballaban-Gil et al., 1996; Billstedt et al., 2005; Creak, 1963; Gillberg & Steffenburg, 1987; Howlin et al., 2004; Kanner, 1971; Kobayashi et al., 1988; Lotter, 1974, 1978; Rutter, 1970). For a review of deceased subjects with autism from the outcome literature, refer to Table 1.

There are four studies that address mortality and cause of death in populations of individuals with autism specifically (Fombonne, 2003a; Isager, Mouridsen, & Rich, 1999; Pickett, Paculdo, Shavelle, & Strauss, 2006; Shavelle & Strauss, 1998; Shavelle, Strauss, & Pickett, 2001). For example, Isager et al. (1999) studied a clinical sample of 341 children in Denmark with pervasive developmental disabilities, including infantile autism, autistic-like conditions, borderline childhood psychosis, and disintegrative psychosis. These subjects were seen as inpatients at the University Clinics of Child Psychiatry between 1960 and 1984, reassessed in 1985, and followed over an average of 24 years. Mortality and emigration information was obtained through the Danish Central Persons Registry. The dates and causes of death were taken from the Register of Causes of Death, which is part of the Danish Institute of Clinical Epidemiology. Annual mortality rates of the group as well as standardized mortality ratios, which are comprised

Table 1

Autism Mortality Rates and Characteristics from Outcome Literature

Study	<i>n</i>	Age	Gender	Cause of Death
Creak, 1963	3/100	10	F	Epileptic fit
		25	M	
		28	M	Choking
Rutter, 1970	2/63			Seizures
Kanner, 1971	1/11	29	M	“Died suddenly”
Kanner, 1973	2/96			Hit by a truck; Died unexpectedly (hx. of seizures)
Lotter, 1974b	1/29	10	M	Not noted specifically, possibly pneumonia and complications of tuberous sclerosis
Gillberg et al., 1987	1/46	8	F	Heart condition
Koybayashi et al., 1992	4/201	6	M	Encephalopathy
		16	M	Self-inflicted head injury
		20	M	Nephritic syndrome
		22	M	Bronchial asthma
Ballaban-Gill et al, 1996	3/102			Complications of psychotropic medication, aspiration pneumonia, accidental drowning
Larsen et al., 1997	2/18	35	M	Internal hemorrhage after traffic accident
		33	M	“Unrecognized volvulus”
Howlin et al., 2004	1/68			Status epilepticus
Billstedt et al., 2005 ^a	6/120	7	F	Status epilepticus
		10	F	Unknown, possibly status epilepticus during sleep
		15	M	Accidental fire
		18	M	Heart surgery complications
		19	F	Brain tumor

^a There were no data on the sixth case in the Billstedt study
Other incomplete data was left blank

from the ratio of observed to expected mortality, were computed. The Kaplan-Meier method estimated the survival function of the group.

Results demonstrated that 12 of the 341 children died during the observation period. The crude mortality rate was 3.5%. The standardized mortality ratio for the group overall was 1.9, indicating almost twice that expected from the general population on matched variables such as age, gender, and length of follow-up period. Causes of death were described to be due to physical diseases such as epilepsy and unnatural causes such as accidents, suicide, and drug overdose. Both severe retardation and normal intelligence were correlated to a relatively high risk of mortality. Level of intelligence for these individuals was based on cognitive testing in only 60% of the sample and clinical judgment alone in the rest of the subjects.

In another mortality study, Shavelle and Strauss (1998) examined 11,347 subjects with autism through use of the California Department of Developmental Services' database between the years of 1980 and 1996. Nonambulatory participants were excluded. Annual Client Development Evaluation Reports (CDERs) were conducted on approximately 182,263 individuals with developmental disabilities through statewide regional centers and provided information regarding entry into the system, as well as demographic, diagnostic, medical, social, and living conditions.

The exposure period to death, as defined in this study, was the individual's date of their first Client Development Evaluation Report to either death, the end of the study, or 3 years from their last CDER. Data from the California Department of Health Services Bureau of Vital Statistics provided a comparison sample of mortality rates in the general population. Life tables were calculated to obtain expected mortality rates for both the

male and female groups; consequently, the life expectancies for those with autism were compared to the general population. The researchers found a statistically significant gender difference for mortality rates across age groups, with females at higher risk for mortality. There was a lower life expectancy for individuals with autism overall.

In a later study conducted by the same researchers (Shavelle et al., 2001), further variables related to mortality such as intellectual ability and cause of death in those with autism was explored. This time, 13,111 individuals diagnosed with autism, who were receiving services from the California Department of Developmental Services, were followed over a period of 14 years in a manner similar to the prior study. Standardized mortality rates were calculated. Again, these were based on the observed deaths in comparison to expected deaths derived from the general population data.

A little over 200 subjects in the California sample died during the observation period. The overall standardized mortality ratio (SMR) was 2.4, signifying a rate over twice that expected from the general population at that same time period. Again, the researchers found a gender discrepancy. Males had a SMR of 1.7 while females had a SMR of 5.5. However, age and cause of death patterns were comparable between males and females, with children between the ages of 5-10 having the highest mortality rates. Those with moderate to severe mental retardation also had a higher risk of death in comparison to those with mild mental retardation or of normal intelligence. All groups had a strong correlation between seizures and death. Other causes of death included nervous system dysfunction, drowning and suffocation (which was more pronounced in the normal and mildly intellectually impaired groups), respiratory disease (seen more

frequently in those with severe mental retardation), physical disease, and other external causes.

Pickett et al. (2006) published another report updating their findings regarding autism mortality. Data were analyzed for the following time period: 1998-2002. The researchers utilized the same methodology as the prior studies. The standardized mortality ratio was 2.6 for the entire sample, which demonstrated excess mortality. The SMRs for the male and female groups were not statistically different from those found previously.

Purpose of the Proposed Study

The aim of this study is to follow up a cohort of adults originally diagnosed with autism using DSM-III criteria in the UCLA-University of Utah Epidemiologic Survey of Autism, as well as another sample of individuals who were suspected of having autistic symptoms but who did not meet DSM-III diagnostic criteria for autism at that time (Ritvo et al., 1989). The names and identifying information of these individuals will be checked against the Utah Population Database (UPDB) to assess current measures of outcome. The following UPDB computerized records will be examined as outcome indicators in this study: death certificates, driver's licenses and identification cards, marriage and divorce records, and birth certificates of offspring.

This follow-up study contributes to our understanding of the outcome for adults with autism in several ways. It provides an opportunity to further conceptualize mortality in adults with autism in a population-based sample. Prior studies specifically investigating autism mortality have utilized clinical or referred populations of adults.

This study allows us to replicate or disconfirm previous findings regarding autism mortality disseminated by researchers such as Shavelle (1998, 2001, 2006) and Isager (1999), from California and Denmark populations. Additionally, this study examines questions concerning whether or not adults with autism become drivers, obtain state identification cards, get married, divorce, and have offspring, which are all areas that have not been previously systematically addressed in the research literature in this manner. All are important facets when considering the quality of life for adults with autism.

Research Questions

1. What are the outcome rates for mortality, driver's license and state identification card attainment, marriage, divorce, and offspring for the DSM-III autism and not DSM-III autism groups?
2. How do these rates compare to the Utah general population over the same time period?
3. How many individuals in both groups have complete address information, including street, city, and state?
4. Are there group differences in outcome obtainment?
5. What factors are related to mortality, driver's license and state identification card attainment, marriage, divorce, and presence of offspring for the groups?

Hypotheses

1) There will be a higher death rate in the DSM-III autism group in comparison to the general population.

2) Cause of death, age, and gender for the deceased autism subjects will be consistent with results found in other studies.

3) Intelligence will be related both to poor (as measured by mortality) and good outcome (defined by having a driver's license, being married, and having offspring).

4) Overall, the percentage of individuals with autism who have obtained good outcome will be small.

CHAPTER II

METHOD

Participants

In this study, we followed up a sample of 316 adults who originally were ascertained as youth as part of the UCLA-University of Utah Epidemiologic Survey of Autism. The initial epidemiologic survey was conducted between 1984 and 1988. The study targeted individuals living in Utah under age 25 who were suspected of having autism and/or were “developmentally delayed” (Ritvo et al., 1989). During the study period, 241 individuals were diagnosed with DSM-III autism, 138 were diagnosed as not having autism through application of DSM-III criteria, and 110 were excluded. At this time, there is no information regarding whether individuals in the not DSM-III autism group met criteria for other disorders or were given a diagnosis during or after the survey. We do know that many subjects were referred because of developmental concerns. Exclusion of subjects was reportedly due to the following factors: failure to cooperate, being above the age criteria, relocation, or loss of contact with the researchers over the course of the survey (Ritvo et al., 1989).

Subjects in the initial study were born between 1960 and 1984 and were between the ages of 3 and 25 when first assessed, with the exception of two older siblings included in the autism group. For a breakdown of Utah born DSM-III autism subjects in

the initial survey by age categories, refer to Table 2. Of the youth classified with autism, 78.8% were male, 79.5% were born in Utah, 66% had an intelligence quotient (IQ) score below 70 based on standardized cognitive tests, 9.7 % came from multi-incident families with more than one child with autism, approximately 95% of the families identified themselves as being of Caucasian descent, and almost 70% of the families ascribed to the Church of Jesus Christ of Latter Day Saints (Ritvo et al., 1989).

Diagnostic Ascertainment

Participants involved in the epidemiologic survey were first identified through a four-level selection process. The first level involved those already known to have autism

Table 2

Age Range Prevalence of Utah Born DSM-III Autism Subjects

Birth Years	Age Range (Years)	Subjects <i>N</i> =190
1980-1984	3-7	44
1975-1979	8-12	66
1970-1974	13-17	44
1965-1969	18-22	25
1960-1964	23-27	11

Adapted from Ritvo et al., 1989; 49 were not born in Utah and 2 male siblings were born in 1950 and 1954

through a prior case finding project conducted by one of the Utah researchers. The second level included voluntary referrals received through lectures and media campaigns targeting children with autistic features or developmental delays. Solicited community referrals constituted the third level. The fourth level was comprised of cases established through record reviews completed at hospitals, state group homes, and residential facilities.

Once the subjects were selected, the researchers collected extensive records for each individual in the study. These included multigeneration pedigree charts, familial medical and disease histories, and a developmental inventory comprised of 500 items (Ornitz, Guthrie, & Farley, 1977). The researchers also obtained medical information consisting of obstetrical, birth, and postnatal records, as well as available psychological, educational, vocational, and residential reports pertinent to the survey (Ritvo et al., 1989).

A three phase comprehensive evaluation was carried out on the youth ascertained in the epidemiologic survey. During the primary phase, two of the UCLA researchers did an independent blind review of all the case records. They used information derived from the records to complete modified versions of the Behavior Observation Scale for Autism (BOS; Freeman, Schroth, Ritvo, Guthrie, & Wake, 1980) and the Ritvo-Freeman Real Life Rating Scale (Freeman, Ritvo, & Yakota, 1986). Together, these were utilized to assess current and historic symptoms of autism. Through the records review process, participants who did not meet criteria for autism according to the Diagnostic and Statistical Manual of Mental Disorders-Third Edition (DSM-III) were categorized as not having autism. The DSM-III requirements for infantile autism (1980) the researchers used to assess cases included the following criteria:

- A. Onset before 30 months of age
- B. Pervasive lack of responsiveness to other people (autism)
- C. Gross deficits in language development.
- D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal
- E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects
- F. Absence of delusions, hallucinations, loosening of associations, and incoherences as in Schizophrenia. (pp. 89-90)

During the second phase of the project, the remaining youth requiring further assessment were seen directly in Utah by a team of clinicians. The researchers met with these participants and their family members in order to gather detailed developmental histories, conduct in person record reviews, and formulate current mental status examinations based on their observations. Historic and current symptoms were again recorded using the modified Behavior Observation Scale for Autism and Ritvo-Freeman Real Life Rating Scale forms. In addition, DSM-III (1980) criteria were again applied to assess autism and not autism cases. In the third and final phase, the clinicians reevaluated undiagnosed subjects and consensus diagnostic decisions were made through case conference review (Ritvo et al., 1989).

Cognitive Ascertainment

The researchers collected information regarding cognitive functioning for the DSM-III autism group during the original survey period. Intelligence quotient (IQ) scores were available for 185 of the males with autism and 50 of the females. As mentioned above, the majority (66%) of the subjects with autism had IQ scores less than 70, falling in the intellectually disabled range. There was also an unequal gender proportion among the lowest scorers, with 52% of females and 38% of males achieving

IQ scores less than 50. IQ information was not available for the subjects not diagnosed with DSM-III autism (Ritvo et al., 1989).

A variety of intelligence tests used to assess cognitive abilities were administered to the youth with autism. Instruments were selected based on the individuals' developmental age and language ability. The following measures were employed: the Wechsler Preschool and Primary Scale of Intelligence (WPPSI; Wechsler, 1967), the Wechsler Intelligence Scale for Children-Revised (WISC-R; Wechsler, 1974), the Wechsler Adult Intelligence Scale-Revised (WAIS-R; Wechsler, 1981), the Stanford-Binet Intelligence Scale (Terman & Merrill, 1960), the Culture Fair Tests (Cattell & Cattell, 1960), the Leiter International Performance Scale (LIPS; Leiter, 1979), the Bayley Scales of Infant Development (BSID; Bayley, 1969), the Denver Developmental Screening Test (DDST; Frankenburg & Dodds, 1967), the Merrill-Palmer Scales of Development (MPMST; Stutsman, 1931), the Slosson Intelligence Test (SIT; Slosson, 1963), and the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn & Dunn, 1981).

Selection Criteria for Current Study

A master diagnostic list differentiating which participants were in the DSM-III autism, not DSM-III autism, and excluded categories was not available at the time the present study was conducted. However, the Utah researchers involved in the original survey possessed several source lists in their own historic records containing both diagnostic information and IQ scores for subjects. There were six source lists with diagnostic data and two different lists with cognitive data. We compared these source

lists in order to compile consensus diagnostic and IQ lists for the participants in the current study. We inputted diagnostic and cognitive data derived from the historic source lists into a database. A graduate student then did a blind check of all the historic data entered. There was 99.9% reliability in the diagnostic data between the first entry and entry check and 100% reliability in the cognitive data between checks.

A decision tree delineating those subjects initially ascertained through DSM-III criteria as having autism, not having autism, or not being diagnosed was strictly followed. With the exception of two older brothers included in the original epidemiologic sample, subjects had to fall into the correct age criteria, meaning they were born between 1960 and 1984. The brothers were part of the DSM-III autism group and were born in 1950 and 1954. Several older participants assessed in the records as either having or not having autism were excluded. Two subjects who only had one record purporting the status of autism were not included in the sample. If there was 100% diagnostic agreement among the available historic source lists, the diagnosis of DSM-III autism or not DSM-III autism was maintained for the current study. If there was any discrepancy in the historic records for either the autism or not autism subjects, these cases were classified as not being diagnosed. Over 80% of the sample categorized as DSM-III autism or not DSM-III autism had either five or six source records with 100% agreement.

The total number of individuals yielded as either having or not having DSM-III autism was lowered through this stringent process in comparison to the original numbers in the epidemiologic survey. However, we decided that a more conservative estimate would be most appropriate when deciphering accurate diagnosis. In the current study, the consensus list included 222 individuals with DSM-III autism and 94 not diagnosed with

autism using DSM-III criteria. As mentioned previously, the diagnostic composition of the not DSM-III autism group is unclear at this point in time. These subjects did not meet DSM-III criteria for autism during the survey but unquestionably had other types of developmental concerns that warranted them being screened for autism.

Procedure

This study was carried out as an activity included in the Genetics of Autism Protocol, approved by the University of Utah's Institutional Review Board. Because current diagnostic criteria in DSM-IVTR are less restrictive than DSM-III criteria, we included both the DSM-III autism positive and negative diagnosis groups. The names of the individuals on the consensus list (222 autism participants and 94 subjects not diagnosed with autism) were submitted for query to the Utah Population Database. In order for a person to be linked within the UPDB, their name must match one or more of the vital or historic records that the computerized database contains. Other identifying information such as the individual's month, day, and year of birth, place of birth, and the names of their parents were also provided to the Utah Population Database to ensure more thorough record linking. This information was taken from the historic records kept by the Utah researchers involved in the original survey.

The Utah Population Database contains almost 9 million records, providing genealogical, demographic, and medical information for 6.5 million unique individuals and documenting 15 million individuals overall on various types of records. The most fundamental feature of the UPDB is its ability to match familial records and histories taken from multigeneration pedigrees. In existence for over 30 years, the UPDB serves

as a unique resource for Utah researchers and provides extensive data sets not available else where in the United States (Utah Population Database, 2005).

The Utah Population Database receives its records from numerous sources. The Utah Department of Health's Bureau of Vital Records supplies the UPDB with birth, death, marriage, and divorce data sets. These vital statistics are updated regularly, most of them on an annual basis. The UPDB maintains 2 million birth certificates from 1947 to 2005 and 700,000 death certificates from 1904 to 2005. Death certificates include Utah Department of Health International Classification of Disease cause of death codes and 1990 Census industry and occupation codes.

Over 500,000 marriage records and 200,000 divorce records from 1978 to 2004 are also housed in the UPDB. Prior to 1989, marriage records contained the names and ages of the wife and husband, the marriage date, and the county where the marriage took place. After 1989, the marriage records also included birth date and place, previous educational information, and the number and type (religious or civil) of marriage. Divorce records are also more complete after 1989. They provide the following information: names, birth dates, educational history of the husband and wife, county where the divorce took place, marriage and divorce dates, number of marriages, number of children, and number of children under age 18 living with the family.

The Utah Department of Public Safety's Driver License Division is another agency that contributes to the Utah Population Database. It provides driver's license and state identification card information for approximately 2.6 million records, including license status, issue date, and records of current and previous addresses. Seventy percent

or more of the individuals listed on one type of UPDB record link to at least one other record type maintained within the system (Utah Population Database, 2005)

The query in the Utah Population Database produced a data file listing which participants and their parents had linked records in their system. The DSM-III autism and not DSM-III autism UPDB records provided the measures of outcome in this study, including death certificates, driver's licenses and state identification cards, marriage and divorce records, and birth records of progeny. The UPDB also gave us marriage, divorce, address and death dates, listings of the death city, county, and state, and the number of offspring for each participant with children. They provided occupation and International Classification of Disease (ICD) codes derived from the death certificates, including diagnosis and cause of death. Additionally, the UPDB supplied the most recent address information on record for participants and their parents, which was taken from the license records.

The period of follow-up for this study was the beginning of the initial survey (1984) until the time we submitted names to the UPDB for record linking (August 4, 2005). This covered a span of 22 years. There was no historical information regarding exactly when during the initial survey subjects were originally assessed. However, we wanted to account for those individuals obtaining outcome measures during the course of the survey period, such as individuals experiencing mortality or those who may have gotten married between 1984 and 1988.

Design

This study utilized a longitudinal (cohort) prospective design examining how many individuals in the DSM-III autism and not DSM-III autism groups had death certificates, driver's licenses, state identification cards, marriage and divorce records, and birth records of progeny. The study was quasi-experimental in that the initial subjects were not randomly assigned to either the DSM-III autism or not DSM-III autism group. Rather, they were assessed initially through epidemiologic methods.

Data Analyses

We examined the data derived from the Utah Population Database through use of the Statistical Package for the Social Sciences (SPSS). We conducted frequency rates for the DSM-III autism and not DSM-III autism groups based on the number of individuals who had death certificates, driver's license and state identification cards, marriage and divorce records, and offspring computerized records within the UPDB. For example, we obtained a mortality rate for the DSM-III autism group by dividing the total number of deaths that occurred during the follow-up period (1984-2005) by the total number of individuals in that group. We also assessed the percentage of individuals who yielded complete address information (including street number, city, and state) for either themselves or their parents. This information was taken from the UPDB license records. Additionally, we examined ICD-9 and ICD-10 codes to determine cause and diagnosis of death.

Chi-square analysis was used to detect between group differences for all outcome indicators, as well as to determine differences in-group characteristics before and after

subject names were submitted to the UPDB. Chi-square is a nonparametric test of statistical significance used to assess whether or not two samples differ in some particular aspect or behavior. Because this study dealt with proportional discontinuous categorical data from two independent samples (i.e., the frequency in which people in the DSM-III autism or not DSM-III autism groups experienced mortality), this technique was utilized. When expected cell frequencies were less than five, a Yates's correction (or continuity corrected chi-square) procedure was implemented. We also calculated two-tailed *t*-tests to evaluate group differences based on continuous data, such as the age and IQ of subjects.

General population data for marriage, divorce, and offspring rates were obtained from the United States Census Bureau for Utah (2005). The prevalence rates for marriage and divorce applied to males, age 15 and over. Offspring rates pertained to women between 15 and 50 years of age who had a birth 12 months prior to the Census reporting. We also found birth rate information from the Utah Department of Health. Driver's license statistics were taken from the United States Department of Transportation Federal Highway Administration within the Office of Highway Policy Information. Specifically, the 2005 Highway Statistics Series, Section III: Driver's Licensing was used. Driver's license rates were applicable to male and female drivers within the total resident population in Utah. Using the information we gathered from the Census, Department of Health, and the Federal Highway Administration, we were able to compare marriage, divorce, offspring, and driver rates within the DSM-III autism and not DSM-III autism groups to the general population. We were not always able to acquire

data that corresponded exactly to the period of follow-up or to the specific ages of our subjects. However, using the 2005 rates was the most viable alternative.

We obtained mortality statistics from the Utah Department of Health in order to compare mortality in the DSM-III autism and not DSM-III autism groups to the general population. The Utah's Indicator-Based Information System for Public Health was used. The general population data was matched for gender, duration of follow-up, and age characteristics. Using this information, we analyzed the crude mortality rates for the DSM-III autism, not DSM-III autism, and general population groups.

Additionally, we used the indirect method to assess excess mortality in the DSM-III autism and not DSM-III autism groups in comparison to the general population. This statistical procedure allowed estimation of the expected number of deaths in both the autism and not autism groups from data obtained from Utah general population mortality rates. We contrasted the number of deaths observed over the study period to our expected number of deaths by means of calculating a standard mortality ratio (SMR). Selvin (1991) defines a standard mortality ratio as “the ratio of the total observed number of deaths to the number expected.” (p. 30). The formula used to compute an indirectly standardized mortality ratio is provided below (Gail & Benichou, 2000):

$$SMR = d / e, \text{ where } e = \sum n_i R_i$$

i = age group

n_i = the index population in age group i

N_i = standard population in age group i

$n = \sum n_i$ = total index population

$N = \sum N_i$ = total standard population

d_i = deaths in index population in age group i

D_i = deaths in standard population in age group i

$d = \sum d_i$ = total number of deaths in index population

$D = \sum D_i$ = total number of deaths in standard population

$r_i = d_i/n_i$ = index population death rate in age group i

$R_i = D_i/N_i$ = standard population death rate in age group i

$r = d/n$ = index population crude death rate

$R = D/N$ = standard population death rate

y_i = number of years in age group I . (p. 873)

The DSM-III autism and not DSM-III autism samples were segregated into age bands (e.g., 0-5, 6-10, 11-18, 19-45). The number of person years each subject contributed to the various age bands over the course of follow-up or until death was calculated. For example, if a subject was 13 years old at the start of the survey and 35 years old at the time of follow-up, they did not contribute any person years to the 0-5 or 6-10 age bands. However, they contributed 5 person years to the 11-18-age band and 12 person years to the 19-45-age band. The number of person years was tabulated for males and females combined and separately. Mortality rates for the same age bands, also segregated by gender, were taken from the Utah population over the same follow-up period. Each of these rates was multiplied by the corresponding cumulative number of person years the subjects contributed in each age band. The sum of all of these results produced an expected number of deaths for the autism and not autism groups. The observed number of deaths was divided by the expected number of deaths to calculate the standard mortality ratio.

Lastly, IQ scores were altered in this study. Because we did not believe there were qualitative differences between IQs less than 50, if an IQ score was assessed at less than 50 during the initial survey, it was recoded to 50 in this study. This was done to preserve the distribution curve and account for extreme outliers. IQ information was available for 217 of the 222 individuals in the DSM-III autism group. Of 217 individuals with historical information regarding IQ, 90 had an IQ less than 50.

CHAPTER III

RESULTS

The present study followed up a cohort of 316 individuals originally ascertained as part of the UCLA-University of Utah Epidemiologic Survey of Autism. Subjects were targeted during the initial survey because they exhibited autistic features or had developmental delays. Through a multiphase evaluation, they were classified as either meeting or not meeting DSM-III criteria for autism. This study examined how many individuals in the DSM-III autism and not DSM-III autism groups obtained basic measures of outcome. Indicators of outcome included how many individuals in both groups had death certificates, marriage and divorce records, driver or state identification cards, and records of progeny. These were derived by checking the names and identifying information of participants against computerized records contained in the Utah Population Database. If a participant had one or more of these types of records, they were considered linked within the UPDB.

The results of the current study are outlined below in six sections. The first section provides demographic information for the samples in relation to gender, place of birth, and age at the time the names were submitted to the UPDB for record linking. Additionally, the intelligence quotient (IQ) scores for the autism participants, which were obtained during the initial survey, are also reported. The subsequent sections address

each of the five research questions proposed at the beginning of this paper. Because the first and second research questions are interrelated they will be covered simultaneously.

Demographic Data

Characteristics of the Total Sample

For a breakdown of all the participants in the DSM-III autism and not DSM-III autism groups on the consensus list by gender, place of birth, and age when names were submitted to the Utah Population Database for record linking, see Table 3. For the autism group only, IQ scores are also provided in Table 3.

Table 3

Characteristics of the Total Sample by Group

	DSM-III Autism	Not DSM-III Autism
Male	177/222= (79.7%)	62/94= (65.9%)
Born in Utah	160/222= (72.1%)	70/94= (74.5%)
Age at UPDB Loading		
Mean (sd) [range]	29.9 (5.6) [21-54.09]	29.6 (5.7) [20.09-45.05]
Initial IQ ^a		
Mean (<i>sd</i>) [range]	65.2 (20.1) [50-137]	Not assessed

^a IQ scores were available for 217 individuals in the autism group

Differences that could have existed between the DSM-III autism and not DSM-III autism groups before the names of the entire sample were submitted to the UPDB for record linking were assessed through chi-square analysis. We did this to determine how similar the two samples were. There was a significant difference between groups for gender, $\chi^2(1, N= 316) = 6.8, p < 0.01$. There were significantly more males in the autism group than in the not autism group before UPDB record linking. There was no significant difference for those born in Utah, $\chi^2(1, N= 316) = 0.19, p > .05$, meaning there were similar numbers of individuals in both groups that were born in Utah. There was also no significant group difference for age at UPDB loading $t(171) = 0.44, p > .05$. Both groups had similar age distributions and almost the exact same mean age at the time their names and identifying information were submitted. In conclusion, the only systematic difference between groups was for gender, with a significantly higher percentage of males in the DSM-III autism group.

Characteristics of Subjects with UPDB Records

The names and identifying information of all participants were submitted to the Utah Population Database to check against their computerized records. If one or more records were found in the UPDB, a subject was considered to be linked within the system. Of the names submitted, records were found for 185 of the DSM-III autism and 84 of the not DSM-III autism subjects. For a breakdown of the linked groups by gender, place of birth, and age characteristics, refer to Table 4. As done in Table 3, IQ scores for the autism group are also listed in Table 4.

Table 4

Characteristics of Subjects with UPDB Records by Group

	DSM-III Autism	Not DSM-III Autism
Linked Records	185/222=83.3%	84/94=89.4%
Male	148/185=80%	56/84=66.7%
Born in Utah	158/185=85.4%	70/84=83.3%
Age at UPDB Loading Mean (<i>sd</i>) [range]	30.2 (5.6) [21-54.09]	29.5 (5.8) [20.1-45.1]
Initial IQ ^a Mean (<i>sd</i>) [range]	65.8 (19.8) [50-135]	Not assessed

^a IQ scores were available for 183 of the individuals in the autism group with UPDB records

Group differences were again assessed to investigate if there were changes in-group compositions based on those participants who had one or more linked records. Chi-square analysis was employed. There was no significant difference between the DSM-III autism and not DSM-III autism groups in the number of individuals who had records that linked, $\chi^2(1, N= 316) = 1.9, p > .05$. The groups were similar in the number of individuals that had records in the UPDB. We can conclude that there was no systematic difference between the DSM-III autism and not DSM-III autism groups that permitted one group to have more individuals with records in the UPDB. After UPDB linking, there still was no significant group difference for those born in Utah, $\chi^2(1, N=$

269) = 0.19, $p > .05$. Both groups maintained proportionate numbers of individuals born in Utah. There was still a significant difference between the DSM-III autism and not DSM-III autism groups for gender, $\chi^2(1, N= 269) = 5.6, p < 0.05$. This showed that there continued to be more males in the autism group, even after UPDB linking. The DSM-III autism and not DSM-III autism groups with UPDB records sustained characteristics similar to the entire sample.

Characteristics of Subjects Who Did Not Have UPDB Records

As illustrated above, there were participants from the overall sample who did not have computerized records in the Utah Population Database. There were 47 subjects comprised from both groups, 37 in the DSM-III autism and 10 in the not DSM-III autism group, who did not have UPDB records. However, 32 of 47 participants (68.1%) without UPDB records had parents with records in the UPDB. Complete address information, including street address, city, and state, was listed for 53.2% of these parents.

Demographic information for the participants, including gender, place of birth, age, and IQ scores when relevant, is provided for both the linked and not linked group in Table 5. Differences between groups that did and did not have UPDB records were assessed through chi-square analysis. The only significant difference found between the linked and not linked group was for those born in Utah, $\chi^2(1, N= 316) = 130.9, p < 0.001$. Individuals that did not have records within the UPDB were much more likely to be born outside of Utah. Of the group that did not have UPDB records, 45 of 47 (95.7%) were born out of state. There was not a significant group difference for gender between the linked and not linked group, $\chi^2(1, N= 316) = 0.04, p > 0.05$, meaning there were not more

Table 5

Characteristics of Subjects With and Without UPDB Records

	Not Linked	Linked
Male	35/47=74.5%	204/269=75.8%
Born in Utah	2/47=4.3%	228/269=84.8%
Age at UPDB Loading Mean (<i>sd</i>) [range]	28.9 (5.4) [21-44]	30 (5.7) [20.1-54.1]
Initial IQ ^a Mean (<i>sd</i>) [range]	62.2 (21.9) [50-137]	66 (20) [50-135]

^aIQ scores were available for 34 of those in the not linked and 183 in the linked groups

individuals of a particular gender who had UPDB records. There was no significant difference for age of subjects at UPDB loading for the linked and not linked groups $t(63) = -1.19, p > .05$, or cognitive ability based on initial IQ scores for the DSM-III autism subjects $t(43) = -0.95, p > .05$. Thus, age and IQ was not related to whether an individual had UPDB records.

Research Question 1

What are the outcome rates for mortality, driver's license and state identification card attainment, marriage, divorce, and offspring for the DSM-III autism and not DSM-III autism groups?

Research Question 2

How do these rates compare to the Utah general population over the same time period?

Mortality, license, marriage, divorce, and offspring rates for all groups are outlined below. These rates were obtained for both the DSM-III autism and not DSM-III autism groups with UPDB records for the follow-up period, 1984-2005. For the rest of the paper, all analyses will refer to those participants who had UPDB records. Mortality and birth rates for the general population were also collected for the length of follow-up; however, driver's license, marriage, and divorce rates for the general population apply only to 2005. There was no information regarding prevalence rates in the general population for state identification cards at the time of analysis.

Mortality

In the DSM-III autism group, 10 of the 185 adults (5.4%) were deceased. In comparison, 8 of 84 adults (9.5%) in the not DSM-III autism group were deceased. According to health statistics obtained from the Utah's Indicator-Based Information System for Public Health, 11,040 individuals of 12,383,263 people within the general population died between 1984 and 2005, age 0-45. This provided a control group matched for age and duration of follow-up period to compare to the rates within the autism and not autism groups. Thus, the crude rate in deaths per 100,000 in the general population was 89.15 (0.09%), with a confidence interval of 87.49 to 90.81.

License and ID Cards

Thirty-one of the 185 adults (16.8%) in the DSM-III autism group had driver's licenses and 100 of 185 (54.1%) had Utah state identification cards. Conversely, 30 of the 84 adults (35.7%) in the not DSM-III autism group had driver's licenses and 26 of 84 adults (30.9%) had state identification cards. According to the Federal Highway Administration, of the total resident population in Utah in 2005, 648 per 1,000 individuals (64.8%) had driver's licenses. Although it is not known when the autism and not autism participants first acquired their driver's licenses, we hypothesize that those with a history of license records in the UPDB feasibly still had them in 2005, allowing for accurate comparisons to the general population. As mentioned above, there was no information available regarding how many individuals within the general population had state identification cards.

Marriage and Divorce

In the DSM-III autism group, 7 of the 185 adults (3.8%) had marriage records. One male divorced after a year of marriage and did not have any offspring. Conversely, 13 of 84 adults (15.5%) in the not autism group had marriage records. Another male in the not DSM-III autism group also divorced after being married for over 5 years; he subsequently remarried within a year of being divorced. Marriage and divorce dates were listed on the UPDB records.

Marriage and divorce data were taken from the United States Census Bureau for Utah (2005) and applied to males 15 years and over within the general population. In 2005, there were 892,853 males in this age range. Of those, 547,455 were married and

66,067 were divorced. All of the married subjects in the DSM-III autism groups were males; however, only 9 of the 13 participants in the not autism group were males. In order to make consistent group comparisons to the general population data, only males married in 2005 were considered. Thus, in 2005, 4.1% (6/148) of the DSM-III autism males were married, 16.1% (9/56) of the not DSM-III autism males were married, and 61.3% of the Utah 2005 general population males were married. Divorce rates for the DSM-III autism and not DSM-III autism groups were very low in 2005. There were no instances of divorce in the not DSM-III autism group in 2005; 17% (1/6) of the DSM-II autism males were divorced. Only 7.4% of the Utah general population males were divorced in 2005.

Offspring

Four of the 185 adults (2.2%) in the DSM-III autism group had offspring. They were all male, yet only 2 of them had records of being married. Three participants had one child each and one subject had three children. Seven of 84 adults (8.3%) in the not DSM-III autism group had offspring. Three of these adults were females, 4 were male, and all had marriage certificates. Four individuals had one child, 2 subjects had two children, and 1 participant had three children.

As with the marriage and divorce data, birth rates for the general population were gathered from the United States Census Bureau for Utah (2005). These rates corresponded to women between 15 and 50 years of age who had a birth 12 months prior to the Census reporting. This category contained 56,659 women. There were 87 per 1,000 women fitting this description. For the autism group, none of the females had

offspring. In the not autism group, 10% (3/28) of the females had offspring. For the general population females in 2005, 8.7% had offspring. Because we do not know when the females in the not DSM-III autism group had their children, we cannot make accurate comparisons to the general population using these 2005 statistics.

We also acquired birth rate statistics from the Utah Department of Health from the Utah's Indicator-Based Information System for Public Health. Between 1984 and 2005, there were 732,727 births and 35,684,804 people in the population. Thus, the birth rate was 20.53 per 1,000 people, with a confidence interval between 20.49-20.58. As stated above, none of the DSM-III autism females had children over follow-up, so the birth rate for this group was zero. However, out of the 3 females who had offspring in the not DSM-III autism group, there were seven children who were born over the course of follow-up. Thus, the birth rate in the autism group was 0% (0/185), the birth rate in the not autism group was 8.3% (7/84), and the birth rate in the general population was 2.1% (20.53/1000). We did not consider the males who had children because their wives, or mothers of their children, were not part of the larger sample.

Research Question 3

How many individuals in both groups have complete address information, including street, city, and state?

Contact Information

Complete address information, including street, city, and state, was assessed from the UPDB license records. Out of 185 individuals in the DSM-III autism group, 128 of

the subjects (69.2%) had complete contact information. Complete contact information was available for the parents of these adults in 176 of 185 (95.1%) of the cases. For the not DSM-III autism group, 51 of 84 adults (60.7%) had complete contact information listed and 80 of 84 adults (95.2%) had complete contact information listed for their parents.

Prevalence rate percentages for participants with driver's licenses, married, deceased, and divorced, as well as birth rates for all groups are provided in Figure 1. As described above, adjustments in the subjects' characteristics such as age and gender were made to allow more appropriate comparisons to the general population. The rates and percentages of all the outcome measures by group are shown in Table 6.

Research Question 4

Are there group differences in outcome obtainment?

We assessed group differences through several different methods. We determined whether or not there were statistically significant differences between the DSM-III autism and not DSM-III autism groups in the number of individuals who had linked UPDB records, death certificates, driver's license and state identification cards, marriage and divorce records, and birth records of progeny through chi-square analysis. We also calculated the difference between the two independent proportions for each outcome measure in each sample and generated their corresponding confidence intervals. For example, we compared the proportion of people in the DSM-III autism group who were deceased to the proportion of people in the not DSM-III autism group who were deceased. The following formula was used (Fleiss, 1981):

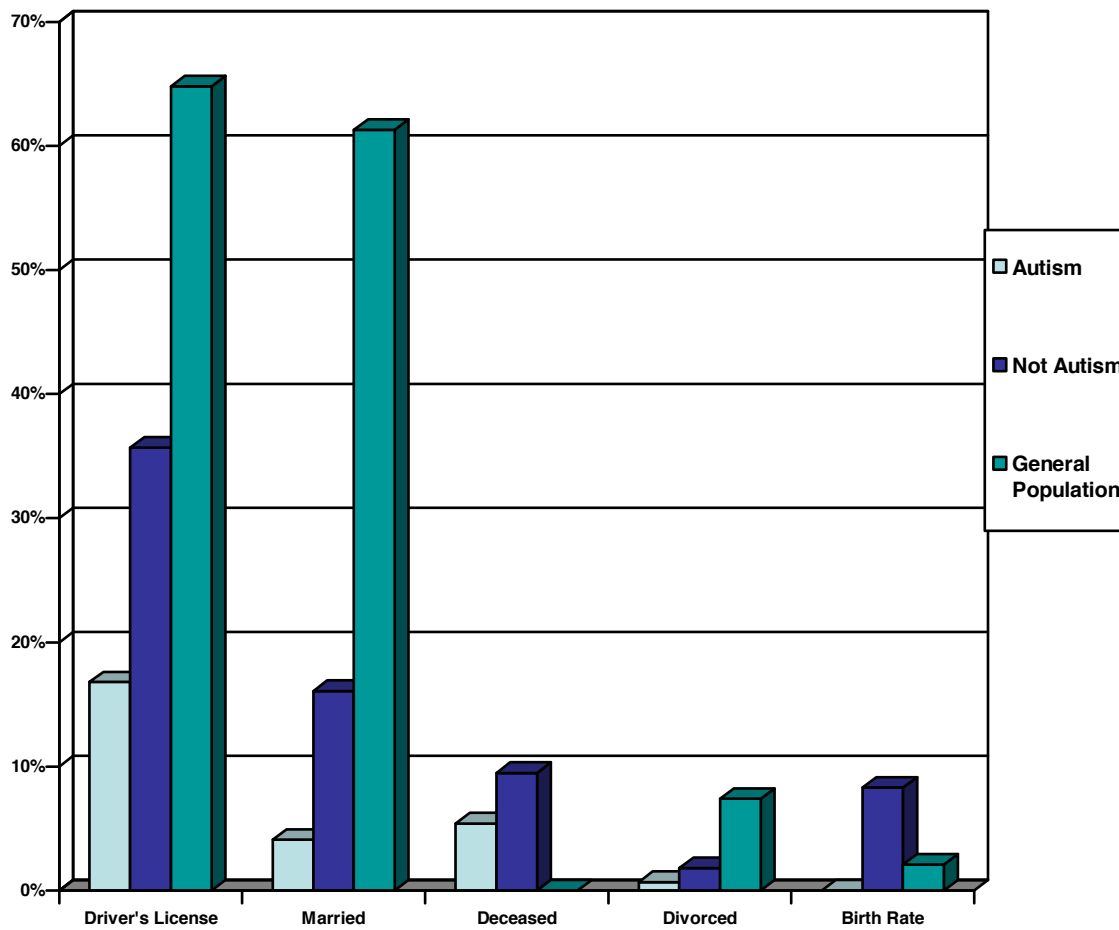


Figure 1

Comparison of Outcome Measure Obtainment by Group

Table 6

Rates and Percentages of All Outcome Measures by Group

Outcome Measure	DSM-III Autism	Not DSM-III Autism	General Population
UPDB Linked Records	185/222=83.3%	84/94=89.4%	Not Applicable
Deceased	10/185 Crude Mortality Rate=5.4%	8/84 Crude Mortality Rate=9.5%	89.15/100,000 Crude Mortality Rate=0.09%
Driver's License	31/185=16.8%	30/84=35.7%	648/1,000=64.8%
State ID Cards	100/185=54.1%	26/84=31.0%	Not Assessed
Married	7/185=3.8%	13/84=15.5%	61.3%
Divorced	1/185=0.5%	1/84=1.2%	7.4%
Offspring	4/185=2.2%	7/84=8.3%	20.53/1,000=2.1%
Proband Address	128/185=69.2%	51/84=60.7%	Not Applicable
Parent Address	176/185=95.1%	80/84=95.2%	Not Applicable

$$(p_2 - p_1) - c_{\alpha/2} \sqrt{\frac{p_1 q_1}{n_1} + \frac{p_2 q_2}{n_2}} - \frac{1}{2} \left(\frac{1}{n_1} + \frac{1}{n_2} \right) \leq p_2 - p_1 \leq$$

$$(p_2 - p_1) + c_{\alpha/2} \sqrt{\frac{p_1 q_1}{n_1} + \frac{p_2 q_2}{n_2}} + \frac{1}{2} \left(\frac{1}{n_1} + \frac{1}{n_2} \right)$$

subscripts 1 and 2 denote the two independent populations

p = proportion in each population

$p_2 - p_1$ = difference between proportions

$q = 1 - p$

n = sample size

$c_{\alpha/2}$ = value cutting off the proportion $\alpha/2$ in the upper tail of standard normal curve

We assessed differences between the DSM-III autism groups and the general population for mortality, driver's license attainment, marriage, and divorce through chi-square analysis and by computing the difference in the outcome proportions of these two groups and their respective confidence intervals. These calculations were done in the same manner as described above with the DSM-III autism and not DSM-III autism groups. Lastly, we examined whether there was a standardized difference between both the autism and not autism group in comparison to the general population in terms of excess mortality. We used the indirect method of calculating a standard mortality ratio to do this. The results are listed below in three separate sections.

DSM-III Autism and Not DSM-III Autism Group Differences

As mentioned above, chi-square analysis showed that there was not a statistically significant difference between the DSM-III autism and not DSM-III autism groups in the number of individuals who had UPDB records, $\chi^2(1, N= 316) = 1.9, p > .05$. For the specific proportion difference values and corresponding confidence intervals by group, refer to Figure 2. The 95% confidence interval for the difference in group proportions for those with UPDB records was -0.03 to 0.15. Because the value of zero is captured in this interval, we can conclude that the difference in proportions between the two groups is consistent with our chi-square analysis. Both groups had similar numbers of individuals with records found in the UPDB.

Chi-square analysis showed there was not a statistically significant difference between the autism and not autism groups in the number of deceased individuals, $\chi^2(1, N = 269) = 1.57, p > .05$. The 95% confidence interval for the difference in group proportions for mortality was -0.04 to 0.12. Because the value of zero is found in this interval, we can again conclude that the difference in proportions for mortality between the two groups is consistent with our chi-square analysis. Both groups are experiencing comparable mortality rates. There was also not a statistically significant group difference for those divorced, Yates $\chi^2(1, N= 269) = 0.036, p > .05$, as evidenced by chi-square analysis. The 95% confidence interval for the difference in group proportions for those

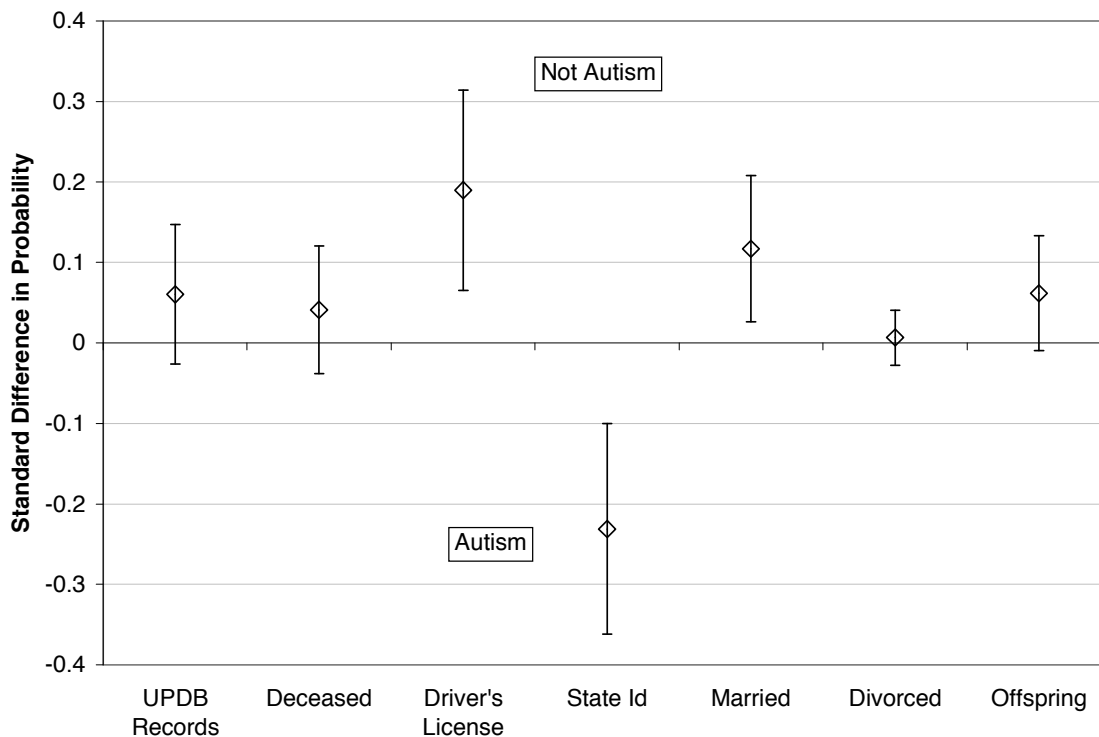


Figure 2

Proportion Differences and Confidence Intervals for the
DSM-III Autism and Not DSM-III Autism Groups

divorced was -0.03 to 0.04. Again, the value of zero was found in this interval, demonstrating no significant group difference for divorce.

As demonstrated through chi-square analysis, significant differences existed between the DSM-III autism and not DSM-III autism groups for several of the outcome measures. There was a significant difference between groups for driver's license, $\chi^2(1, N= 269) = 11.8, p < 0.001$. For the specific proportion difference values and corresponding confidence intervals by group, refer to Figure 2. The 95% confidence interval for the difference in group proportions for those with driver's licenses was 0.06

to 0.31. Because the value of zero is not captured in this confidence interval, we can conclude that there is a difference between groups for driver's license, with more adults in the not DSM-III autism group with driver's licenses. This is consistent with the chi-square analysis. There was a significant difference in groups for identification card, $\chi^2(1, N= 269) = 12.3, p < 0.001$. The 95% confidence interval for the difference in group proportions for those with state identification cards was -0.36 to -0.1. Again, results are commensurate with chi-square analysis, showing more adults with autism having state identification cards. There was a significant difference between groups for marriage, $\chi^2(1, N= 269) = 11.4, p < 0.001$. The 95% confidence interval for the difference in group proportions for those married was 0.03 to 0.21. Because the value of zero was not found in this interval, this suggests that more individuals in the not DSM-III autism group are married, a result consistent with the chi-square analysis. There was a significant difference in groups for offspring, Yates $\chi^2(1, N= 269) = 4.2, p < 0.05$. The 95% confidence interval for the difference in group proportions for those with offspring was -0.01 to 0.13. Unlike the other proportion difference comparisons, the value of zero is contained in the confidence interval for offspring. This implies that although chi-square analysis found a statistically significant difference between groups for offspring, this result may be erroneous, and there may not be a true difference between groups for offspring.

Phi (ϕ), which is similar to Pearson product moment r , was used as a measure of association in this study; ϕ^2 equals the amount of shared variance. The chi square value demonstrates whether there is a statistically significant difference between groups based on some variable, such as license obtainment, and provides a measure of the significance

of the association. Conversely, phi informs us on the degree of the association. Thus, if there is a significant difference between groups, ϕ provides an indication of the magnitude of this difference. Fleiss (1981) defines the phi coefficient as “a measure of the degree of the association between characteristics A and B which is derived from χ^2 but is free of the influence of the total sample size, n , $\phi = \sqrt{\chi^2/n}$ ” (p. 59).

When phi is close to zero, we can infer that there is little or no association. As phi approaches one, then the association becomes almost perfect. According to Fleiss (1981), any phi value less than 0.30 or 0.35 suggests a marginal association.

The association between diagnostic groups (DSM-III autism and not DSM-III autism) and driver’s license obtainment $r(267) = 0.21, p < .01$ state identification card attainment $r(267) = 0.21, p < .01$ marriage $r(267) = 0.21, p < .01$ and offspring $r(267) = 0.14, p < .05$, showed relatively small associations. For example, 4% of driver’s license obtainment can be explained or predicted by assignment in the DSM-III autism or not DSM-III autism groups. Other undetectable factors account for 96% of license attainment. In all instances of group differences, variables other than diagnostic group are accounting for the majority of the shared variance. Although there were statistically significant group differences based on the χ^2 values, these findings suggest that the differences between the autism and not autism groups for driver’s license, state identification card, marriage, and offspring are small when factoring in the effect size between diagnostic group and outcome measure.

DSM-III Autism and General Population Group Differences

Differences between the DSM-III autism groups and the general population for mortality, driver's license obtainment, marriage, and divorce were calculated through two methods. Chi-square analysis was conducted to assess statistically significant group differences. Additionally, the proportion of individuals in each group obtaining each outcome measure was contrasted and corresponding confidence intervals containing the difference values were generated. For the specific proportion difference values and corresponding confidence intervals by group, refer to Figure 3.

Chi-square analysis showed a significant difference between the DSM-III autism and general population groups for mortality $\chi^2(1, N= 12,383,458) = 586.47, p < 0.001$. The 95% confidence interval for the difference in group proportions for those deceased was -0.09 to -0.02. Both of these analyses demonstrated significantly more deceased individuals in the autism group and the confidence interval does not contain zero. There was a significant difference between groups for driver's license obtainment $\chi^2(1, N= 1,185) = 147.277, p < 0.001$. The 95% confidence interval for the difference in group proportions for those with driver's licenses was 0.42 to 0.55. Again, the value of zero is not captured in the confidence interval. More people in the general population have driver's licenses. There was a significant difference between groups for marriage $\chi^2(1, N= 893,001) = 204.53, p < 0.001$. The 95% confidence interval for the difference in group proportions for those married was 0.54 to 0.61. There was a significant difference between groups for divorce Yate's $\chi^2(1, N= 893,001) = 8.81, p < 0.01$. The 95% confidence interval for the difference in group proportions for those divorced was 0.05 to 0.08. The confidence intervals in the latter two proportional comparisons did not contain

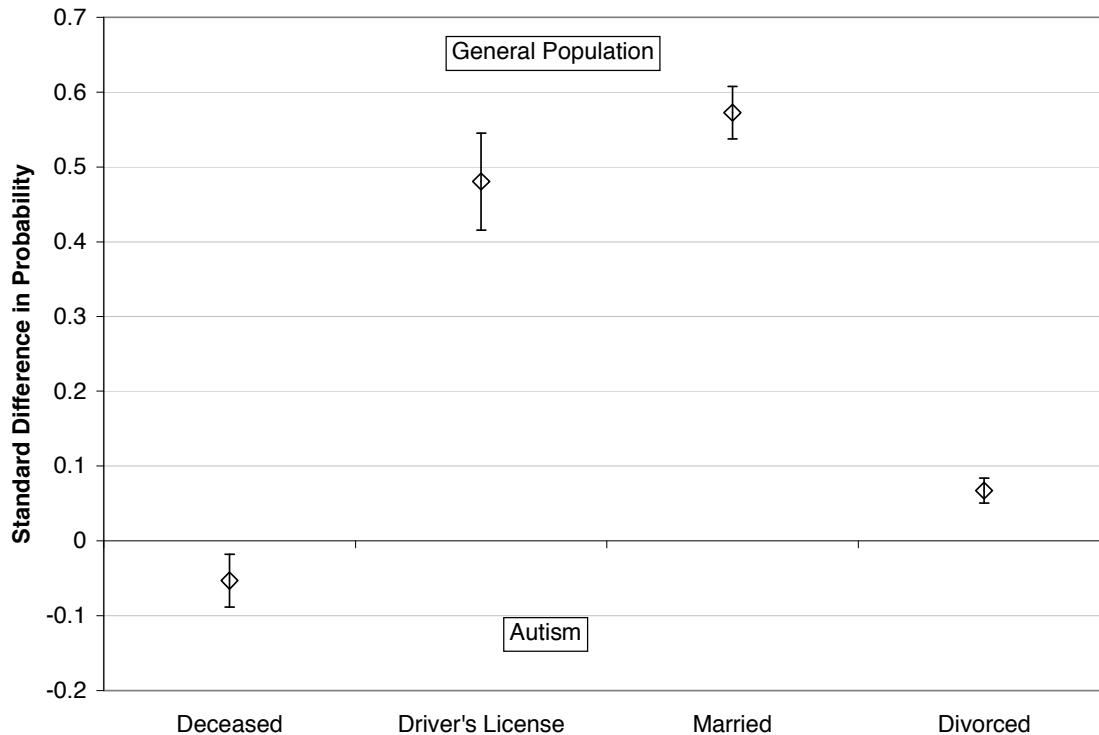


Figure 3

DSM-III Autism and General Population Proportion

Differences and Confidence Intervals

zero. Individuals within the general population were more likely to be married and divorced. The effect sizes, as measured by phi, showed marginal effects.

Standardized Group Comparisons for Mortality

We calculated standard mortality ratios (SMRs) for the DSM-III autism and not DSM-III autism groups, using mortality rates from the general population. These rates were adjusted for gender, length of follow-up, and age (e.g., 0-5, 6-10, 11-18, 19-45).

The standard mortality ratio is derived by dividing the observed number of deaths by the expected number of deaths estimated by using general population rates. An SMR that is greater than one indicates excess mortality in relation to the general population. The standard mortality ratios for both groups, segregated by gender and age bands are provided in Table 7 and 8. Results showed that subjects in both the DSM-III autism and not DSM-III autism groups exhibited excess mortality.

The DSM-III autism group had an overall SMR of 2.9, indicating a mortality rate on average almost three times that of the general population. Excess mortality was more evident ($SMR = 20$) in the 6-10 age band for the entire group. Mortality was most pronounced for females ($SMR = 7.5$) in comparison to males ($SMR = 1.8$). The SMR for females and males within the various age bands varied widely.

The not DSM-III autism group had an overall SMR of 5, showing excess mortality of five times that, on average, of the general population. This overall SMR was also higher than the autism group. As seen in the autism group, a similar gender pattern emerged in the group of subjects not assessed with DSM-III autism. Females had higher excess mortality ($SMR = 7.5$) than males ($SMR = 3.8$).

Research Question 5

What factors are related to mortality, driver's license and state identification card attainment, marriage, divorce, and presence of offspring for the groups?

Table 7

Standard Mortality Ratios (SMRs) for Autism Group

Age Category	22 Year State Mortality Rate (Per 100,000)	Autism Group Person Years	Autism Group Expected Deaths	Autism Group Observed Deaths	SMR (Obs/Exp)
ALL SUBJECTS					
0-5	154.02	132	0.2	0	0
6-10	20.11	470	0.1	2	20
11-18	50.95	1206	0.6	4	6.7
19-45	120.08	2125	2.6	4	1.5
Total			3.5	10	2.9
FEMALES					
0-5	133.11	18	0	0	0
6-10	15.69	80	0	0	0
11-18	33.43	235	0.1	1	10
19-45	74.98	453	0.3	2	6.7
Total			0.4	3	7.5
MALES					
0-5	173.8	114	0.2	0	0
6-10	24.32	390	0.1	2	20
11-18	67.8	971	0.7	3	4.3
19-45	165.06	1672	2.8	2	0.71
Total			3.8	7	1.8

Table 8

Standard Mortality Ratios (SMRs) for Not Autism Group

Age Category	22 Year State Mortality Rate (Per 100,000)	Autism Group Person Years	Autism Group Expected Deaths	Autism Group Observed Deaths	SMR (Obs/Exp)
ALL SUBJECTS					
0-5	154.02	91	0.1	0	0
6-10	20.11	234	0.05	1	20
11-18	50.95	554	0.3	2	6.7
19-45	120.08	872	1.1	5	4.5
Total			1.6	8	5
FEMALES					
0-5	133.11	41	0.1	0	0
6-10	15.69	81	0	1	0
11-18	33.43	186	0.1	1	10
19-45	74.98	272	0.2	1	5
Total			0.4	3	7.5
MALES					
0-5	173.8	50	0.1	0	0
6-10	24.32	153	0	0	0
11-18	67.8	368	0.2	1	5
19-45	165.06	600	1	4	4
Total			1.3	5	3.8

Good Outcome

Good outcome in this study was defined as those individuals with driver's licenses, married, and with offspring. Factors related to good outcome are described below.

Intelligence

Intelligence appears to be related to indicators of good outcome for adults with autism. For the DSM-III autism group, IQ scores were available for 98% of those with identification cards, and for all of those who had driver's licenses, were married, and had offspring. The distribution of initial IQ scores for the autism subjects attaining these outcome indicators is listed in Table 9. Although there was variability in the distribution of scores, the average IQ score fell in the low average range ($M = 88.7$, $SD = 22$) for those obtaining driver's licenses and the average range for those with marriage ($M = 102.4$, $SD = 34.8$) and offspring ($M = 107.8$, $SD = 20.8$) records. Conversely, individuals in the DSM-III autism group with state identification cards had a mean IQ falling within the impaired range ($M = 63.8$, $SD = 16.2$), suggesting that higher IQ is not related to this particular measure of outcome. There were 11 individuals in the autism group who had records of both a driver's license and a state identification card. Their IQ scores were higher, on average ($M = 78.91$, $SD = 18.19$) than those with just an identification card.

Additionally, initial IQ scores were available for the vast majority of the individuals in the DSM-III autism group who did not have driver's licenses (98.7%), marriage certificates (98.9%), offspring records (98.9%), and state identification cards (100%). Two-tailed *t*-tests were performed to assess group differences in IQ scores for

Table 9

Gender and Initial IQ Related to Outcome for Adults with Autism

Outcome Variable	% Male	IQ mean (sd) [range]
Driver's License	30/31= 96.8%	88.87 (21.98) [51-135]
Married	7/7= 100%	102.43 (34.81)[50-135]
Offspring	4/4= 100%	107.75 (20.81)[83-132]
State ID Cards ^a	77/100= 77%	63.84 (16.16) [50-110]

^a IQ scores were available for 98 of 100 individuals with state identification cards

those with and without license, marriage, and offspring records. There were significant group differences in IQ for driver's license $t(36) = 6.71, p < 0.001$, marriage $t(6) = 2.88, p < 0.05$, and offspring $t(3) = 4.09, p < 0.05$, but not for state identification card $t(147) = -1.39, p > 0.05$ records. We can conclude from these findings that the individuals with DSM-III autism who had driver's license, marriage, and offspring records had higher initial IQs, on average, than those who did not. Individuals with or without state identification cards had comparable IQ scores, on average.

Gender

The impact of gender on outcome for the DSM-III autism subjects was also assessed. The percentage of males with driver's licenses, state identification cards, married, and with offspring is provided in Table 9. Because the DSM-III autism group was predominantly male, we computed single sample z -tests to detect the effect of gender on outcome obtainment. There was a significant difference for driver's license ($z = -2.18$, $p < .01$), but not for state identification card ($z = 0.55$, $p > .05$), marriage ($z = -1.32$, $p > .05$), or offspring ($z = -1$, $p > .05$). This shows that more males with autism obtain driver's licenses, a result independent of the fact that there were a significantly higher proportion of males in the DSM-III autism group to begin with.

For males in the not DSM-III autism group, 20/26 (76.9%) had state identification cards, 21/30 (70%) had driver's licenses, 9/13 (69.2%) were married, and 4/7 (57.1%) had offspring. When we accounted for the proportion of males in the sample size, we did not find significant gender differences for driver's license ($z = -0.254$, $p > .05$), state identification card ($z = -0.81$, $p > .05$), marriage ($z = 0.11$, $p > .05$), or offspring ($z = 0.39$, $p > .05$). Thus, gender does not appear to be related to those who do not attain these measures.

Poor Outcome

Poor outcome was measured by instances of mortality. Gender, age, initial IQ (for the DSM-III autism group only), and cause of death for all of the deceased individuals are outlined in Table 10 and Table 11.

Table 10

Case Summaries of Deceased Individuals with DSM-III Autism

<i>n</i>	Gender	Death Age	IQ	ICD Death Codes/ Record Notations
1	M	26	39	Convulsions/ Had Seizures
2	F	25	39	Other ill defined and unspecified causes of mortality/ ID card
3	M	14	41	Unspecified anomaly of brain, spinal chord, & nervous system Student at special school for children with disabilities
4	M	8	19	Epilepsy, unspecified/ Had seizures
5	M	15	68	Mucopolysaccharidosis/ Had metabolic disorder
6	M	19	15	Nonsuppurative otitis media & Eustachian tube disorder
7	F	11	25	Other specified disorders of the nervous system/ Had Rett's
8	M	6	29	Acute lymphoid leukemia
9	F	25	35	Metabolic Disorder
10	M	18	35	Open wound of hip and thigh

Seven of the 10, or 70% of the deceased subjects in the DSM-III autism group were male. Six of the 10, or 60% were age 18 or under, and could be categorized as being of school age when they died. All of the deceased individuals had an initial IQ less than 70. Cause of death was attributed to accident or injury, nervous system difficulties, epilepsy and/or convulsions, cancer, metabolic dysfunction, ear problems, or was unspecified from the available International Classification of Disease (ICD) codes.

Table 11

Case Summaries of Deceased Individuals with Not DSM-III Autism

<i>n</i>	Gender	Death Age	ICD Death Codes/ Record Notations
1	M	21	Pneumothorax
2	M	22	Unspecified Mental Retardation; Infantile cerebral palsy, quadriplegic; Pneumonitis due to inhalation of food or vomitus
3	M	20	Severe Mental Retardation/ Student at Training School
4	F	7	Congenital anomalies of Nervous System-Microcephalus
5	F	17	Unspecified disorder of metabolism/ Special education student
6	M	16	Unspecified Mental Retardation
7	F	24	Status epilepticus; Asphyxia/ Never Worked
8	M	23	Other specified anomalies of the heart

In comparison, 5 of the 8, or 62.5% of the deceased subjects in the not DSM-III autism group were male. Three of the 8, or 37.5% were age 18 or under.

The ICD mortality codes listed cause of death being a result of or associated with collapsed or inflammation of the lung, mental retardation, neurological disorder of increased head circumference, metabolic disorder, epilepsy and/or suffocation, and heart abnormalities.

Considering that the number of deceased individuals with DSM-III autism is small, the original sample was predominantly male, the majority of subjects had initial IQ

scores less than 70, and a large proportion of the initial subjects were of school age during most of the follow-up period, concluding that gender, IQ, and age are uniquely related to mortality in the individuals with autism in our study warranted further exploration. These characteristics were already distinctions in our original sample.

Therefore, to address these confounding factors, we conducted several different statistical analyses for the DSM-III autism group. We computed a single sample z -test to analyze the effect of gender on mortality, a two-tailed t -test comparing the mean initial IQs of those deceased versus those alive, as well as another t -test examining the mean age of those alive at the time of UPDB loading versus the mean age the deceased individuals would have been at the time of UPDB loading. These analyses showed no significant differences for gender, ($z = 0.52, p > .05$), or age at UPDB loading, $t(11) = -.21, p > 0.05$, but they did yield a significant difference for initial IQ, $t(26) = -6.27, p < 0.001$. This suggests that lower IQ and younger age are distinctly related to mortality for the DSM-III autism participants.

CHAPTER IV

DISCUSSION

This study is unique in that it is population-based. Very few studies have investigated the outcome of individuals with autism using epidemiologic samples (Billstedt et al., 2005; Gillberg & Steffenburg, 1987; Lotter 1974a, 1974b; von Knorring & Hagglof, 1993). Rather, the vast majority of outcome studies have utilized small, clinically referred samples of subjects originally ascertained in childhood or adolescence and followed them prospectively into adulthood. Because of its epidemiologic design, the findings of this study can be generalized to the overall population of adults who were diagnosed with autism in the 1980s and not just those who have sought clinical services. This study elucidates the outcome of adults with autism in relation to mortality, driver's license and state identification card attainment, marriage, divorce, and presence of offspring. Major findings of this study are presented below.

Major Findings of Research Questions

Mortality

Mortality was elevated in the DSM-III autism group. Three of the four population-based follow-up studies in the literature reported on the mortality of their samples (Billstedt et al., 2005; Gillberg & Steffenburg, 1987; Lotter, 1974b). For

example, there was one deceased individual in the Lotter (1974b) study, one deceased male in the Gillberg and Steffenburg (1987) study, and there were six deceased individuals in the Billstedt et al. (2005) study. The crude mortality rate found in this study (5.4%) was most closely aligned with the crude mortality rate (5%) found in the Billstedt et al. (2005) study. When combining all of the reports, factoring the various sample sizes utilized, the cumulative mortality rate for all the prior population-based studies was approximately 4%. Considering all of the incidences of mortality described in previous autism follow-up studies (see Table 1), the cumulative mortality rate is approximately 3%. Additionally, the Isager et al. (1999) sample had a crude mortality rate of 3.5% and Shavelle et al. (2001) reported on a crude mortality rate of 1.5% in their sample. Thus, while it is important to acknowledge the heterogeneity of samples in making comparisons across studies and over time, the crude mortality rate in this study appears to be only slightly higher than found in previous mortality research.

Mortality in the autism group was also significantly higher than the general population, as evidenced by chi-square analysis and through examination of the difference between the proportions of individuals in each group who were deceased. We were also able to contrast the observed mortality in the autism group in comparison to that expected based on general population rates by calculating a standard mortality ratio (SMR). The overall standard mortality ratio for the autism group showed that individual with autism, on average, had excess mortality of almost three times that of the general population after adjustment for age and gender. Females and individuals between 6 and 10 also had the highest standard mortality ratios. Thus, there appears to be a trend for females and school-aged children with autism to experience higher rates of excess

mortality than expected. These findings are commensurate with other studies specifically looking at mortality in individuals with autism (Isager et al., 1999; Pickett et al., 2006; Shavelle & Strauss, 1998; Shavelle et al., 2001). More research with larger and more clearly defined samples is needed in order to understand why these gender and age differences exist.

Death in the autism subjects was associated with low IQ, young age, and medical diseases. Cause of death was attributed to seizures or convulsions in 20% of the sample. Other causes of death were due to nervous system difficulties (20%), metabolic disorder (20%), accident and/or injury (10%), cancer (10%), ear problems (10%), and unknown causes (10%). Other research corroborates the correlation between the causes of death (such as seizures, nervous system dysfunction, and accidents) found in this study, low IQ, and young age with mortality for those with autism (Isager et al., 1999; Shavelle et al., 2001).

An unexpected finding of this study was that mortality was also elevated in the sample of adults not meeting DSM-III criteria for autism during the original epidemiologic survey. In fact, the crude mortality rate (9.5%) and overall standard mortality ratio ($SMR = 5$) were both higher in this group than the autism group. However, chi square analysis showed no significant difference between the autism and not autism groups for mortality. We can interpret this to mean that both the DSM-III and not DSM-III groups experienced increased mortality and these rates were not statistically different from one another.

It is not known exactly why both groups had higher rates of mortality. Future research may help answer this question. It is hypothesized from the review of the data,

such as IQ scores, anecdotal notations in the historical records, and ICD mortality codes, that elevated mortality rates could be explained by both groups having lower cognitive abilities than those within the general population. All of the deceased autism subjects had initial IQ scores less than 70 and almost 40% of the not autism deceased subjects had diagnosis at death or causes of death related to mental retardation. Although there is not a universal definition for those with a developmental delay, the term often is synonymous with individuals delayed in meeting developmental milestones and is in some instances equated to mental retardation or low scoring children on IQ or developmental measures (Petersen et al., 1998). Thus, it is plausible that individuals in the not DSM-III autism group also had severe cognitive impairments. Mental retardation may be one manifestation of medical syndromes affecting overall health and mortality risk. It does not cause death but reflects impaired development of the brain and other vital organs.

Research shows decreased life expectancy in intellectually disabled populations, especially those with profound mental retardation (Bittles et al, 2002; Durvasula & Beange, 2002; Gustavson, Umb-Carlsson, & Sonnander, 2005; Maaskant, Gevers, & Wierda, 2002; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). At this point in time, however, we can only make tentative speculations that lower cognitive functioning appears to be related to mortality for both groups. Additionally, without having initial IQ scores for the not DSM-III autism group, we cannot explain to what extent cognitive functioning can be implicated.

The co-occurrence of medical diseases may be another factor influencing increased mortality in the autism group. The researchers involved with the epidemiologic survey (Ritvo et al., 1990) reported that a proportion of the autism subjects also had

comorbid diseases, some of which were known to impact the central nervous system functioning. These included viral and bacterial infections (8/233=3.4%), chromosome and genetic aberrations (12/233=5.2%), metabolic disorders (7/233=3%), congenital skeletal anomaly (1/233=0.4%), Tourette's syndrome (2/233=0.9%), Rett's syndrome (4/233=1.7%), deafness (2/233=0.9%), eye disorders (3/233=1.3%), and seizures (43/233=18.5%). Although the prevalence rates of most of these diseases were rare in the original subjects and we can only speculate how many subjects in the current sample had these comorbidities, it is likely that concurrent medical diseases may have influenced increased mortality rates.

It is important to address mortality in subjects with autism for a number of reasons. Knowing whether individuals have an increased risk of mortality helps answer questions about life expectancy for parents and health providers. Also, research can then guide policy, prevention and treatment practices based on which causes are related to autism mortality.

License Obtainment

Very few people in both the DSM-III autism and not DSM-III autism groups had driver's license records in comparison to the general population. Less than a fifth of the autism subjects, a little over a third of the not autism participants, and almost two-thirds of those in the general population had driver's licenses. There was also a significant difference between the autism group and the general population in driver's license obtainment as shown through chi-square analysis and by comparing the proportions of individuals in each group with licenses. More males with autism than females had

driver's licenses, even when the proportion of males in the original sample size was accounted for. Higher IQ was also related to driver's license obtainment.

More of the adults with autism had state identification card records than those in the not autism group. This difference could be attributed to the adults with autism applying for state identification card as an alternative form of identification if they were unable to obtain a driver's license. We hypothesize that a majority of the individuals without driver's licenses lack the level of functioning and/or skills required to be a Utah driver.

Marriage, Divorce, and Offspring

As with license obtainment, there were few participants in both the DSM-III autism and not DSM-III autism groups married or divorced in comparison to the general population. The number of individuals with offspring was also very low in this study. The percentage of autism subjects married in this study (3.8%) is somewhat smaller than Howlin (2004) reported. In her review of 16 outcome studies, 6% of the subjects were reportedly married. There was also just one instance of divorce in both the DSM-III autism and not DSM-III autism groups; the male in the latter group later remarried. The low divorce and offspring rates for those with autism appear to be consistent with prior research (Howlin, 2003, 2004).

The core features of autism, notably impairments in communication, social relatedness, and restricted interests or behavior, may make it difficult to navigate an intimate relationship with another person such as is required in marriage. Howlin (2004) outlined the difficulties spouses or partners of individuals with autism face in the

following description: “the problems generally experienced by partners are... namely problems in communication, in sharing, in understanding, expressing or responding to feelings and emotions, and difficulties relating to inflexible, stereotyped and repetitive patterns of behaviour” (p. 314). Kanner’s (1971) detailed case study descriptions also help conceptualize this issue. Although one of his subjects did marry and have a child, the others reportedly were not interested in formulating relationships with the opposite sex, found intimate relationships to be terrifying, or interpreted that members of the opposite sex were not interested in them. Two of these subjects lacked an interest in women because of the financial ramifications. Women reportedly “cost too much money” and another subject stated that he “can’t waste money on a girl that isn’t serious” (Howlin, 2004, pp. 22-23).

Despite these challenges, there were 7 males in the autism sample who were married and 4 males with offspring. Higher IQ was shown to be related to those few that were married and had children. Additionally, the social support systems inherent in Utah culture may foster the long term success of relationships for those with autism who are married and have families. Utah has the highest birth rate in the nation (Martin et al., 2003) and a strong emphasis on family values. These positive cultural influences could plausibly enhance and promote the long term stability of those married and with children.

Contact Information

The majority of participants in both groups had complete contact information listed for themselves or their parents. This supports the feasibility of contacting participants in future outcome studies.

Overall Outcome

Good outcome in this study was defined as those individuals with driver's licenses, married, and with offspring. As noted above, very few individuals in both the DSM-III autism and not DSM-III autism groups obtained good outcome as evidenced by these standards. Good outcome for the DSM-III autism group was related to the initial IQ of these subjects. Those with driver's license, marriage, and offspring records had a mean IQ in the low average to average range. They also had significantly higher IQs, on average, than those with autism without licenses, married, or with offspring.

We categorized poor outcome as those individuals who were deceased. Both groups had excess mortality in comparison to the general population. Death in the autism group was also related to initial IQ and young age.

Group Differences

There were statistically significant differences between the DSM-III autism and not DSM-III autism groups for several of the outcome indicators, including driver's license and state identification card obtainment, marriage, and offspring. However, the magnitude of these effects was relatively small. Other factors outside of diagnostic ascertainment in the DSM-III autism and not DSM-III autism categories seem to be contributing more to outcome obtainment. These could include observed variables such as cognitive ability, gender, and age as well as unaccounted factors not addressed in this study.

There were not significant differences between the groups in the number of individuals that had records in the Utah Population Database, those deceased, or those

divorced. It is feasible that the samples sizes in this study were not large enough to have sufficient power to detect group differences. Fleiss (1981) defines power as “the probability of failing to find the specified difference to be statistically significant” (p. 34). In order to address this, we conducted a power analysis for unequal sample sizes utilizing the generalization of Casagrande's method proposed by Fleiss (1981). Specifically, software developed by Dupont and Plummer from the Biostatistics Department at Vanderbilt University was used.

The results of this analysis demonstrated that there were not enough subjects in the DSM-III autism and not DSM-III autism groups to detect significant group differences in the number of individuals that had UPDB records and those who were deceased or divorced. Power was found to be less than .70 for the current number of subjects. Because it was not feasible to add more participants to each group, we must instead consider that we may not have had enough power to detect differences when interpreting results. Some researchers (Kehle, Bray, Chafouleas, & Kawano, 2007; Thompson, 2007; Sanabria & Killeen, 2007) propose using confidence intervals, effect sizes, and replication statistics rather than relying on p-values to determine the significance of differences.

Implications for Future Research

Future research should focus on those individuals with autism with apparently good outcome, such as those that are licensed drivers, have married, and have offspring. Specifically, questions investigating the predictor variables that facilitate better outcome should be addressed. For example, are there intrinsic characteristics related to

intelligence, adaptive functioning, or language ability that foster better outcomes? How do medical conditions and/or psychiatric comorbidity, such as epilepsy, depression, or anxiety correlate to outcome? Alternatively, do external factors more readily supply explanations for good outcome in adults with autism, such as the degree and level of support systems provided from the community, friendships and familial relationships, early intervention, and/or independence as exhibited through consistent employment and residential status?

Along with examining predictors of good outcome, investigating the similarities between the DSM-III autism and not DSM-III autism groups is also critical in future studies. Due to changing diagnostic criteria between the various revisions of the Diagnostic and Statistical Manual of Mental Disorders (e.g., DSM-III vs. DSM-IV), there may be a number of individuals in the not DSM-III autism group who would currently be classified as having an autism spectrum disorder, under DSM-IV diagnoses of Autistic Disorder, Asperger's Disorder, or a Pervasive Developmental Disorder-Not Otherwise Specified. Reorganizing the groups based on present day classification systems may alter how outcome is characterized in this study. Additionally, examining how many of the individuals assessed as not having DSM-III autism in the 1980s but who now meet current diagnostic criteria for an autism spectrum disorder would aid in answering questions about increasing prevalence rates of autism. As other researchers have proposed, changing definitions for autism over time impacts the interpretation of the "autism epidemic" and increased prevalence rates (Fombonne, 2003b, 2005; Gernsbacher, Dawson, & Goldsmith, 2005; Kielinen, Linna, & Moilanen, 2000; Wing & Potter, 2002).

In a direct assessment study of DSM-III autism cases now underway, 3 subjects previously diagnosed as not having autism according to DSM-III criteria in the original survey now meet DSM-IVTR criteria for an autism spectrum disorder. These 3 subjects have subsequently participated in the genetics of autism studies conducted at the Utah Autism Research Program after their involvement in the initial epidemiologic survey. The University of Utah Institutional Review Board's Genetics of Autism Protocol was followed at the time of their participation. We have had contact with some of these individuals personally and have also spent time interviewing their family members and collecting information about them. A synopsis of each of the three cases is described below.

Case 1

The first subject is a 40-year-old female. According to parental reports, she was diagnosed with Asperger's syndrome in the early 1990s. Through involvement in our ongoing studies, she met our research criteria for a pervasive developmental disorder on the Autism Diagnostic Observation Schedule-Generic (ADOS; Lord et al., 2000). She achieved a full scale IQ falling within the average range, as evidenced by her performance on the Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 1997). The results of her cognitive testing indicate that she has a relative strength in verbal abilities and a relative weakness in processing skills. She lives independently, although her apartment is paid for through governmental assistance. She does not work presently and relies heavily on the support and guidance of her parents.

This participant had records that linked within the Utah Population Database. She was born in Utah and both she and her parents reside there currently. She has a driver's license record, but reportedly does not drive at this point in time. She is not married and does not have any children.

Case 2

The second individual is a male in his late 30s. His parents portrayed him as having "classic autism" and described him as having a delay in language and petit mal seizures during childhood. He met DSM-IVTR criteria for autism on the Autism Diagnostic Observation Schedule-Generic and the Autism Developmental Interview (ADI; Lord et al., 1994). His WAIS-III full scale IQ score places him in the impaired range of cognitive functioning.

This subject also had linked records during the Utah Population Database search. He was not born in Utah but currently resides in Utah with his parents. He has never had a job but does possess a state identification card. His linked UPDB records show no history of a driver's license, marriage, divorce, or offspring.

Case 3

The third case is a deceased male. We do not possess as much information on this particular subject in comparison to the others; most of what we know about him stems from parental report. His parents stated that he was diagnosed with autism, was "low functioning," and exhibited behavioral difficulties during childhood. He died in his early

20s, reportedly from a grand mal seizure or sleep apnea. The autopsy report was reportedly inconclusive.

This subject's name also resulted in linked Utah Population Database records. He was not born in Utah and lived with his parents when he was alive. Outside of information derived from his death certificate, he did not obtain any of the outcome indicators examined in this study.

Limitations of the Present Study

There are at least five limitations inherent to the present study. The consensus list we utilized to differentiate the DSM-III autism and not autism groups was incomplete and did not include the entire sample of 241 individuals assessed with DSM-III autism in the initial survey, or the 138 ascertained as not having DSM-III autism. It will be important to replicate the methods used in the current study to reassess our findings if we are able to acquire the full data set. We hope to be able to collaborate with the original UCLA researchers in future efforts to obtain the initial records of all subjects. Then, we will have a more thorough conception of how many individuals from the original DSM-III autism and not DSM-III autism group are deceased, are drivers, have state identification cards, marry, divorce, and have offspring.

A second limitation is that we were unable to follow up with all of the subjects in the DSM-III autism and not DSM-III autism groups from our consensus list. A proportion of the subjects (16.7% in the DSM-III autism and 10.6% in the not DSM-III autism group) did not have records in the Utah Population Database. The only systematic difference between the people who had records versus those who did not was the

subject's place of birth. Subjects born in Utah had significantly higher success rates with UPDB record linking. We hypothesize that the people who did not have UPDB records were not different from the sample that did have records (i.e., more or less likely to have a driver's license). The UPDB staff (personal communication, 2007) provided the following explanation as to why records do not typically link in the database:

We can only link people who have records in Utah. If they were not born in Utah and have not married, do not drive and have not died, we will not link them. The genealogy records from the family history library do not cover people born recently very well, i.e. after about 1950, so we can only link them if they show up on a vital record or driver's license. The other reason for not linking is lack of information, name changes or incorrect information on the records. The incorrect information could occur on the Autism records or it could occur on our UPDB records.

A third limitation involves how data within the Utah Population Database are maintained and collected. The UPDB does not contain marriage and divorce records prior to 1978 or after 2004. Although it is unlikely that subjects assessed from the original survey were old enough to marry or divorce before 1978, as the oldest subject would have been 18 at that time and there was only a year of follow-up time (2004-2005) where these records were not available, it is feasible that a few married or divorced cases may have been missed. Also, the UPDB license records are taken from a subset provided by the Driver's License Bureau. Thus, the search may have failed to identify some of the subjects who obtained driver's licenses and state identification cards over the follow-up period. We anticipate that these missed counts are minimal; however, the possibility of incomplete cases must be considered.

Additionally, the International Classification of Disease codes taken from the Health Department and 1990 Census industry and occupation codes were sometimes difficult to decipher and often did not provide thorough information. This accounts for a

fourth limitation. For example, we know that one of the DSM-III autism cases that died from “other specified disorders of the nervous system” had Rett’s Disorder. The Rett’s diagnosis is not listed on the death record. More current classifications of mortality, such as codes listed in Medicaid records may illustrate more comprehensive explanations of mortality factors and causes.

Interpretation of the cognitive functioning of the individuals with DSM-III autism in relation to outcome constitutes a fifth limitation. Initial intelligence quotient (IQ) scores must be construed with some trepidation due to the variability issues within subjects and over time, especially those participants who were administered cognitive assessments prior to age five during the initial survey period. IQ is not stable during early childhood and can be difficult to interpret for those with autism spectrum disorders. It is unclear from the historic records exactly when cognitive functioning was assessed. Most likely, the vast majority of IQ tests were administered during the epidemiologic study between the years of 1984 and 1988, but prior accounts of IQ taken from clinical records may also have been used if the researchers were unable to assess intellectual functioning. Additionally, different types of assessments (including both verbal and nonverbal instruments) were utilized, making comparisons challenging. Measurement error in baseline IQ is unknown and likely to be large for a number of reasons.

Conclusions

This study greatly contributes to our understanding of the outcome of adults ascertained with autism in the 1980s. It is the first of its kind to specifically address how many individuals with autism are deceased, obtain driver’s licenses and state

identification cards, marry, divorce, and have offspring from an epidemiologic standpoint. Future studies that address characteristics of both the DSM-III autism and not DSM-III autism groups could prove to be very fruitful in further conceptualizing the adult outcome of those with autism. The high percentage of subjects in both groups and/or their parents who have listed complete address information taken from UPDB license records supports the feasibility of contacting individuals in future outcome studies. This study will be an important foundation for those studies. It may also help guide future policy decisions, prevention and treatment guidelines regarding autism mortality.

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