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AUTISM AND WORK: THE IMPACT OF COMORBIDITY ON EMPLOYMENT

by

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A THESIS

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KAREN HARRIS

MEDICAL SOCIOLOGY

ABSTRACT

There is a growing population of adults with Autism Spectrum Disorder (ASD) in the United States that desire participation in the workforce, yet this population is the least employed out of those with disabilities. This study is framed in a theoretical underpinning of stigma, and undertaken to determine if comorbidity (physical or mental or both) and social support are key factors in employment among the ASD population. Using data from the Interactive Autism Network (IAN) Research Database, nested logistic regression was performed on 222 adults ranging in age from 18-71 who completed the survey on the IAN website. Descriptive analysis shows that the majority of this sample has both mental and physical comorbidities, live with their spouses and/or kids, do not receive financial support from other family members, are female, highly educated, non-Hispanic white, and over age 30. After adjusting for age, education, sex, and race, results find that mental comorbidity and education are significant factors in employment outcomes among the ASD population. This research could be an important factor in policy development, and suggests that for successful employment of ASD individuals, accommodations may need to be made for comorbid mental disorders.

Keywords: Autism, ASDs, comorbidity, employment, social support

DEDICATION

I would like to dedicate this thesis to my family, especially my children. I have strived to teach my children the importance of an education throughout their lives. Returning to college in my forties, earning two undergraduate degrees, and obtaining a graduate degree in my fifties are my endeavors at practicing what I preach. To my children: never lose sight of your goals, even if unforeseen events delay your accomplishments. It is never too late to achieve your dreams!

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CHAPTER ONE

INTRODUCTION

In the last 20 years throughout the United States, the prevalence of an Autism Spectrum Disorder (ASD) diagnosis has steadily increased, with ASD diagnoses growing faster than any other developmental diagnosis (Cavagnaro 2003). ASD diagnoses have continued to increase significantly in recent years (Chappel and Somers 2010). In 2000, for example, the Centers for Disease Control and Prevention (CDC) estimated the prevalence of an ASD diagnosis at a rate of 1 in every 150 children (CDC 2012). The most recently released findings (for 2010) estimate that 1 in 68 children now have an ASD (CDC 2013). Most research has been conducted on children, but previous research on adults has found that 50-75% of ASD individuals are unemployed (Mawhood, Howlin and Rutter 2000; Hurlbutt and Chalmers 2002; Howlin, Goode, Hutton et al. 2004). Given the large increases in ASD diagnoses among children, and the fact that ASD is a lifetime diagnosis, the issue of employment among this population will become increasingly more pressing overtime.

Research indicates that people with disabilities are not as likely to be employed as those without disabilities (Blackorby and Wagner 1996; Wagner, Cadwallader, and Marder et al. 2003). One reason is that employment for people with disabilities is often more limited in scope; another reason is that people with disabilities have to contend with stigma, which discredits the person and reduces the person to being discounted, and not seen as whole (Goffman 1963). Disabled persons may look or act differently than the non-disabled, and this may lead to being labeled, stereotyped, and discriminated against. According to Link and Phelan (2001), there are unequal outcomes among those that are labeled and those that are labeled experience status loss and discrimination. The status loss and discrimination makes it hard for the disabled person to participate fully in society, such as gaining and maintaining employment. It is even harder for those with an ASD to participate in society; they have deficits in communication, social skills, and have different, often disruptive, behaviors.

Although parental loss of productivity among the ASD population has been researched, more research needs to be conducted in loss productivity among the ASD population itself. The purpose of this research is to gain insight as to why productivity is lost among the ASD population itself. Although autism symptoms (such as a lack of social skills) may hinder employment, there may be other factors at play. Could comorbidity (two or more forms of psychopathology in the same individual) symptoms, or stigma stemming from the comorbidity, be a factor in deterring employment of these individuals? Is social support a factor? Can social support suppress the stigma assigned to these individuals and lead to increased employment?

As mentioned, persons with disabilities are not as likely to be employed as those without disabilities, and it has been found that those employed with an ASD earn less and work fewer hours than other disabled groups (Cimera and Cowan 2009). Using data from Wave 5 (2009) of the National Longitudinal Transition Study-2 (NLTS2), Roux, Shattuck, Cooper, et al. (2013) found that since leaving high school only 53.4% of ASD individuals have ever worked outside the home for pay, which was the lowest rate among the disability groups examined.

Double jeopardy, or occupying two lower status roles (such as being female and black) is systematic (King 1988), and may be a factor for those with an ASD looking for employment. The term double jeopardy can also be understood through the feminist theory of intersectionality (Crenshaw 1989; Collins 1998). Intersectionality was developed to combat the idea that the experience of multiple social statuses, such as gender, race/ethnicity, or sexuality, was universal and was not contingent on one's membership in other groups. For example, being a woman is fundamentally different than being a black woman. Intersectionality involves multiple and simultaneous forms of discrimination and can occur when a person has at least two devaluing identities, such as belonging to a minority ethnic group and being female, or having a disability and being female. Each identity, or category, interacts with the other and they are experienced simultaneously, adding a dimension to discrimination that cannot be fully understood when looking at each identity separately. In terms of ASD, the disability of having an ASD may be fundamentally different for individuals based on the other social statuses they employ. For example, ASD individuals often have difficulties with social niceties of situations. In our patriarchic society, women are socialized to be accommodating and polite. Women with an ASD may be more harshly socially sanctioned than men with an ASD given that they have both the disability and have transgressed gender appropriate behavior.

Social support may help negate some of the negative factors associated with ASDs and any accompanying comorbidities, increasing the likelihood of employment.

Social support has been shown to enhance psychological and physical well-being (Pottie, Cohen, and Ingram 2009), and could be even more needed by those with an ASD. However, stigma could also prevent social support by devaluing and discrediting the individual, thereby reducing social support. If individuals with ASDs do not drive, there is no public transportation available, and they have no social support system to help provide transportation to a job, obviously employment would not be possible.

The effects of the continuing increase in the ASD population can be felt in the economic, political, and social arenas, as more and more resources, both public and private, are earmarked for programs serving this population of individuals. These programs include Medicaid and Social Security programs, such as Supplemental Security Income (SSI), and vocational programs. According to the National Institute of Neurological Disorders and Stroke (NINDS) (2009), ASDs are lifelong disorders; thus, those diagnosed as children will have the diagnosis as adults. Since ASD is a lifelong disorder, it is imperative that research be conducted to help ASD individuals participate fully in society, and to help discover ways to reduce the costs to society.

The financial costs of having an ASD are very high. According to Amendah, Grosse, Peacock, et al. (2011), children with ASDs are routinely given behavioral interventions, with an estimated cost of $40,000 to $60,000 per child annually. Also, it is estimated that the lifetime incremental societal costs of ASDs is $3.2 million per capita (Ganz 2007), with lost productivity being one of the largest components of these costs. Additional research needs to be conducted in the area of productivity in order to discover factors to help minimize these societal costs.

A study conducted by Taylor and Seltzer (2012) found that only between 4.6-11.3% of adults with an ASD were employed. An analysis conducted on the second National Longitudinal Transition Study (Wave 5, 2009) by Newman, Wagner, Knokey, et al. (2011) found that ASD individuals were the least employed of any disability group, with only 63.2% having held a job up to eight years after finishing high school; only 37.2% were employed at the time of the interview. Other studies have found that 50-75% of ASD individuals are unemployed (Mawhood et al. 2000; Hurlbutt and Chalmers 2002; Howlin, Goode, Hutton et al. 2004). This has a tremendous impact on society, leaving the taxpayers and government to shoulder the financial costs of those not earning wages in the ASD population.

ASD individuals have trouble with communication, behavior, and social interaction; all of these skills are important in obtaining and maintaining employment. Hendricks (2010) reviewed the previous research on ASD and employment, and found that barriers to employment for ASD individuals include problems in vocational training, cognitive functioning deficits, behavioral problems, high levels of stress and anxiety, and psychiatric comorbidity. Using the 2001 Rehabilitation Services Administration database, Schaller and Yang (2005) found that the absence of a comorbid disorder was significantly related to success in competitive employment.

One reason for the underemployment of ASD individuals is that they have deficits in social skills (Rao, Beidel, and Murray 2008). According to the America's Promise Alliance (2007), social skills are as important in today's labor market as academic skills. Entry into the workforce often begins with low skill jobs; low skill jobs tend to be service jobs, where social skills are important. It is important to note that employment provides not only income; it is an important part of each individual's life, and provides a "source of identity" (Tsang 2003:25), contributing to physical and mental well-being (ibid.). Also, without work, a person may fall into poverty, which is limiting financially and socially (ibid.). Thus, social skills training are needed for the ASD population to be employable at the secondary level and skills training should possibly continue at the post-secondary level (Rao, et al. 2008). However, social skills training do not relieve the stigma attached, as those with ASDs will still have social deficits that cannot be hidden.

There are many reasons that social stigma may be assigned to an ASD individual. People may not understand why an ASD individual behaves differently, and may also feel threatened by the behavior. Blame for the inappropriate behavior may be placed on the person in lieu of the disorder. Communication difficulties may also add to social stigma, as interaction may be impacted negatively. In the conceptualization of social stigma put forth by Jones, Farina, Hastorf et al. (1984), conditions are unequally stigmatized. There are three criteria that may lead to high stigmatization: etiology (the person is seen as responsible for the condition); concealability (the condition is not able to be hidden easily); and peril (the condition is seen as capable of bringing harm to others). Concerning etiology, the general public may not be aware that there may be a biological reason for the condition, or that behavioral difficulties are inherent in the ASD, and may blame the individual for inappropriate behavior. Regarding concealability, those with an ASD walk and hold their bodies differently, and may also have comorbid conditions that are noticeable. The different behaviors and language used may be misunderstood, and others may consider themselves in peril when around an ASD individual.

Goffman (1963) identifies three types of stigma: body (physical), character (personal) and tribal (social). All three types of stigma can be found among the ASD population. In addition to the physical comorbidities (such as sleep and gastrointestinal issues) suffered by many ASD individuals, an unusual gait can also be found among the ASD population, as well as difficulty in fine or gross motor skills. Although there is no "mark" on the individual with an ASD, the way an ASD individual moves and the degree to which the body is controllable is seen by all, and is physical in nature. As for character stigma, the mental comorbidities suffered by an ASD individual can be seen as character deficiencies. In fact, Goffman (ibid.) mentions how those with a mental illness can be seen as weak in character. Many ASD individuals have comorbid mental diseases such as anxiety, depression, obsessive-compulsive disorder (OCD), as well as other comobidities, which can lead to stigma and discrediting of the person. Even some physical ailments such as allergies, gastrointestinal problems, and sleep issues can be looked upon as a person being weak and different from the norm, leading to stigma. Tribal stigma presents itself once the individual is labeled as having an ASD. Comorbidities, either physical or mental, would increase tribal stigma. Individuals with ASDs have differences in behavior than the general population; in fact, deficits in social, behavioral, and communication are the core components when assessing an ASD. Social cues are often missed or not understood by individuals with an ASD, behaviors do not fit the norm, and deficits in communication can make interaction difficult. Thus, one can see how all three stigma types could be applied to a person with an ASD.

By definition, those with ASDs have a social impairment, and they cannot conceal their disability. Their behavior is sometimes disruptive, and this can lead to the devaluation and discrediting of the person. Not being able to conceal a disability, as well as being disruptive, leads to stigma (Jones et al. 1984). The accompanying stigma could lead to a direct form of discrimination, such as refusal to hire the stigmatized person. Also, the form of discrimination could vary, depending on the severity of the disorder (Link and Phelan 2006).

However, another reason that ASD individuals may be less likely to be employed could stem from the comorbidity that is found in individuals along the ASD spectrum. As early as 1985, it was reported by Rumsey, Rapoport, and Sceery that 86% of autistic males in their study had compulsive behavior, and other studies have noted high comorbidity as well. Comorbidity is present in 83% of the ASD population, according to the CDC (2012). It could be that symptoms from comorbidity keep these individuals from working, not the ASD, or that they interfere with the amount of hours they can work. It may be that the ASD and the comorbidity combined is what keep the individual from obtaining or retaining employment.

Stigma is also associated with comorbidity. Küey (2008) found that in those with mental and physical disabilities, the stigma from the mental disability formed the basis for stigma for comorbid physical disabilities. Thus, stigma stemming from comorbid disabilities could make a person more wary of the disabled individual, or of hiring the disabled individual with more than one disability. This study is undertaken to assess the impact of physical and mental comorbidity of ASD individuals on gaining employment, as well as the role that social support may have in the employment of ASD individuals.

Social support could play a mediating role and lessen the negative impact of comorbid disorders among the ASD population. Social support acts as a buffer to stress, reduces morbidity and mortality, and lessens exposure to psychosocial stress (House 1987). Given the high comorbidity and anxiety present in the ASD population, along with other concerns such as transportation among this group, social support could be a significant factor in successful employment among the ASD population.

While conducting an online search of ASD studies, it became apparent that the majority of studies conducted concerning ASDs are on children. The Autism Society of America (2013) estimates that 60% of costs are in adult services. Consequently, research needs to be undertaken on the adult ASD population. Discovering factors that help an ASD individual obtain or retain employment are areas where research would be helpful in lowering the individual and societal costs of ASD disabilities. The results of research in this area could have major effects on economic and other policies in the present and future concerning the ASD population.

Problem Statement

Employment is an important aspect of social life, providing not only income, but a "source of identity" (Tsang 2003:25), and also contributes to mental and physical well-being. ASD individuals are faced with a high unemployment rate (Cameto, Marder, Wagner et al. 2005; Hendricks 2010). This is not just a problem for the ASD individuals and their families; but also a societal problem, as society supports these unemployed individuals through various publicly funded programs, such as Medicaid and SSI. ASD diagnoses are increasing across the globe (Autism Society of America 2006; Chappel and Somers 2010; CDC 2013). Given the large increases in ASD diagnoses among children, and the fact that ASD is a lifetime diagnosis, this issue of employment will become increasingly more pressing overtime.

A major aspect of ASD individuals are deficits in social skills (Rao et al 2008). In today's labor market, social skills have become as important as academic skills (America's Promise Alliance 2007). As the ASD adult population grows, more adults with ASDs will be looking for employment. The unemployment rate of ASD individuals may increase, as well as the societal financial cost of supporting these individuals. Thus, research in the area of job attainment and retention for ASD individuals is warranted.

One area of research that can contribute to the knowledge base concerning employment among ASD individuals is research on how or if the comorbid diseases found among the ASD population impact their ability to work and retain employment. Social support (or lack thereof) may also contribute to employment outcomes. The purpose of this paper is to answer this general research question: what factors play a role in employment among the ASD population? To that end, does comorbidity play a role in employment among the ASD population? Is social support a mediator between comorbidity and employment?

If comorbidity is a deterrent among those with ASD that keeps them from working, attention would need to be focused on lessening the behaviors associated with the comorbidity, or on lessening the stigma associated with comorbidity. These interventions could be addressed when other job training is given; or, medication may need to be prescribed for the comorbidity, if it has not been treated. Educating those without disabilities may help relieve the misunderstanding and added stigma applied to those with comorbidites.

Having people who we can rely on and that love, value, and care about us contributes to psychological and physical well-being (Pottie et al. 2009). In general, those receiving social support are healthier (Billings and Moos 1982; Broadhead, Kaplan, James et al. 1983; Leavy 1983). House (1987) found that social support acts as a buffer to stress, reduces morbidity and mortality, and lessens exposure to psychological stress. Given that the ASD population has social, communication, and behavioral deficits, as well as high comorbidity (including anxiety), social support may be a necessary component for success in employment outcomes among this population.

Purpose of the Study

The high unemployment rate among the ASD population is problematic for society, as society shoulders the responsibility of helping to support this group. Poor social skills have been identified as one possible pathway that ASDs result in lower levels of employment (Rao, et al. 2008). However, there may also be other factors, such as stigma of the ASD population, lack of social support of those with ASDs, and comorbidity among this population, that are relevant to employment attainment and employment retention; thus, research in the field of employment, social support, and comorbidity among the ASD population is warranted. Identification of factors related to employment may help to create programs to address deficits, helping adults with ASDs to gain and retain employment. The purpose of the present study is to add to the knowledge base concerning employment among ASD individuals; specifically, to determine if comorbidity is a factor impacting employment among the ASD population, and to understand the role social support plays in ASD employment. This paper also provides a theoretical viewpoint of how stigma may be a barrier to employment among the ASD population. Employment attainment and retention would benefit not only the individual with an ASD, but society as a whole, as the societal economic and financial costs would be lowered by employment of the ASD population, especially full time employment. This research is undertaken to see if comorbidity is a factor in employment outcomes among ASD individuals, and if social support plays a mediating role in employment outcomes. Examining the impact of comorbid diseases and social support in this population could lead to a better understanding of the difficulties surrounding the employment of individuals with an ASD, thus this study is undertaken to assess the impact of mental and physical comorbidity on employment among the ASD population, as well as the mediating role social support may play in employment.

CHAPTER TWO

LITERATURE REVIEW

In order to understand how ASDs impact society, one must first understand how ASDs impact the individual. To accomplish this, one must understand what ASDs encompass. Thus, a review of ASDs follows.

What are ASDs?

The CDC (2012) and The National Institute of Mental Health (NIMH) (2013) defines ASDs as a group of developmental disorders that are characterized by deficits in social interaction, communication, and behavior. The National Institute of Environmental Health Sciences (NIEHS) (2013) concludes that ASDs cause "severe impairment in thinking, feeling, language, and the ability to relate to others." There are common traits among the disorders that include deficits in eye contact, as well as stereotypical and repetitive behavior (NINDS 2009). ASDs are diagnosed using guide lines set forth in the Diagnostic and Statistical Manual (DSM) from the American Psychiatric Association (NIMH 2013). The cause of autism has yet to be discovered, but it is now believed that genetics play a role in the development of ASDs. Environmental factors are also being researched to see if there is a relationship between the environment and ASDS. Research being conducted includes studies on air pollution and vaccinations as a cause of ASDs, as well as other environmental factors.

The DSM-IV-TR (APA 2000) lists five disorders under ASD; Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Pervasive Personality Disorder-Non Otherwise Specified, and Rett's Disorder. ASDs are categorized under the heading of Pervasive Developmental Disorders (PPDs). Each disorder on the spectrum has unique characteristics. The cognitive and intellectual abilities range from mild to severe, and are unique to the individual, as is the social, communication, and behavioral deficits, which also range from mild to severe. The deficits are usually present before the third year of life. It should be noted that the DSM-V was released in 2013; however, the individuals used in this research were diagnosed with the DSM-IV-TR and earlier versions. The research cited in this study was also conducted using earlier versions of the DSM, thus, the DSM-IV-TR is used in this study.

It is important to note that the CDC lists only Autism Disorder, Asperger's Disorder, and Pervasive Personality Disorder-Not Otherwise Specified (PPD-NOS) as ASDs; other institutions include Rett's Disorder and Childhood Disintegrative Disorder. However, the data set used in this research does not mention Rett's Disorder. The categories listed are Autism or Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, Childhood Disintegrative Disorder, Pervasive Developmental Disorder (different from Pervasive Developmental Disorder-Not Otherwise Specified), Autism Spectrum Disorder, and no longer has an ASD diagnosis, thus these categories are to be considered as the definition of ASDs in this research.

History of Autism and ASDs

The term autism derives from two Greek words; aut, meaning self, and ism, implying an orientation or state (Trevarthen, Aitken, Papoudi et al. 1998). In the United States, Leo Kanner (1943) was the first scientist to use the term autism in his paper "Autistic Disturbances of Affective Contact." Kanner conducted case studies on 11 children whose conditions and behaviors were so uniquely different than what had been previously reported he felt it necessary to document the peculiar aspects of their personalities. Kanner found that all 11 children showed an "*inability to relate to themselves*" (ibid: 242) since birth. Some of these children had been labeled schizophrenic, and others labeled as feebleminded. The children's parents reported that the children were "self-sufficient"; "like in a shell"; "happiest when left alone"; "acting as if people weren't there"; "perfectly oblivious to everything about him"; "giving the impression of silent wisdom"; "failing to develop the usual amount of social awareness"; "acting almost as if hypnotized" (ibid.). One can see that the social aspect of these children's lives were significantly different than their peers; enough so that their parents were concerned about their development and sought professional help. Kanner realized this was not the same as schizophrenia, where one withdraws from society; this syndrome was evident from the beginning of the children's lives, and was an "extreme autistic aloneness" (ibid.). Kanner also detailed the "excellent rote memory" (ibid: 243) of these children. Kanner detailed all other peculiarities of these 11 children, and called for follow-ups of these children's lives as they aged. Kanner believed the autistic conditions were caused exogenously (which could lead to stigma).

In 1944, Hans Asperger studied four boys who had a pattern of deficits and assets and called these characteristics autistic psychopathy (AP), which he considered to be a personality disorder based on a continuum where normal personality existed. He found that these children were eccentric and withdrawn, but mostly gifted and did have some degree of social integration despite their peculiarities concerning social interaction and communication. Asperger noted that AP corresponded to Kanner's autism, but felt that there was a genetic component to the disorder, and that it was not caused from outside factors. Asperger felt that AP was a lifelong and stable personality that would not disintegrate over time. Asperger also stated that some close interpersonal relationships were possible with AP.

Lorna Wing (1981) detailed Asperger's AP in an English-language journal, which made the scientific community aware of the disorder, and called the disorder Asperger's Syndrome (AS), which is still used today. Wing also noted that these children, even in the first year of life, lacked interest or pleasure in human company, and stated that AS may occur in children with learning disabilities. Wing is the one that proposed these disorders were a spectrum of autistic disorders, and had a triadic component consisting of impairments in social interaction, communication, and imagination (Hippler and Klicpera 2003).

In 1980, the psychiatric community included ASDs in the DSM-III, under the heading of Pervasive Personality Disorders. The manual was updated in 1994 (DSM-IV), in 2000 (DSM-IV-TR), and in 2013 (DSM-V). As mentioned, there are five disorders that are considered ASDs in the DSM: Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder, Pervasive Personality Disorder-Not Otherwise Specified, and

Rett’s Disorder. All of these disorders have deficits in social integration, social communication, and social behavior.

Modern (or conventional, standard, or traditional) Western medicine is the primary source for health care in the United States (Cockerham 2010). The CDC (2013) states that autism is not curable, and there are no medications that can treat the core symptoms. Furthermore, medication is usually prescribed for comorbid pathologies such as focus problems, depression, seizures, anxiety, and energy. Treatments are categorized into four groups: behavior and communication approaches, dietary approaches, medication, and controversial health care modalities treating the person as a whole, called complementary and alternative medicine (CAM). Although no medicine can cure ASD or treat ASD symptoms, the U.S. Food and Drug Administration (FDA) approved two antipsychotic drugs to treat severe tantrums, aggression, and self-injury; risperidone and aripripazole.

ASD Data and Statistics

Prevalence and Incidence Rates

ASD prevalence has increased dramatically over the last few decades. According to the CDC’s National Health Interview Survey (NHIS), parent reported ASDs have increased almost fourfold between the surveillance periods of 1997-1999 and 2006-2008 (Boyle, Boulet, Shieve et al. 2011). The CDC’s (2012) Autism and Developmental Disabilities Monitoring (ADDM) Network found a 78% increase in ASD prevalence between 2002 and 2008. Blumberg, Bramlett, Kogan et al. (2013) found that between 2007 and 2011-2012, parent-reported ASD prevalence increased from 1.16 to 2.00%, with increases in diagnoses being observed in all age groups. The prevalence of ASD diagnoses is continuing an ongoing trend, both in the United States and other countries (Fombonne 2006; Boyle et al. 2011; CDC 2012).

Using data from the CDC's ADDM Network 2000-2008 (CDC 2012), the dramatic rise in the prevalence of ASD diagnoses in recent years can easily be discerned. In 2000, with six ADDM reporting sites, the prevalence was 6.7 per 1,000 children, translating to 1 in 150 children. In 2004, the prevalence rate was 8.0 per 1,000 children, translating to 1 in 125 children having an ASD diagnosis, with eight ADDM sites reporting. In 2006, with eleven ADDM sites reporting, the prevalence rate rose to 9.0 per 1,000 children, translating to 1 in 110 children receiving an ASD diagnosis. For 2008, with fourteen ADDM sites reporting, the prevalence rate rose to 11.3 per 1,000 children, translating to 1 in 88 children receiving an ASD diagnosis. The latest report from the CDC states the prevalence rate to be 14.7 per 1,000 children, which is an increase to 1 in 68 children having been diagnosed with an ASD (2013).

There are many reasons for the increase in the prevalence of ASDs. Better diagnostic criteria, the definition of autism changing over time, as well as the age of diagnosis all contribute to better and more diagnoses (Powell, Edwards, Pandit et al. 2007). Incidence rates are not widely used in ASD studies, as the onset is usually present at birth, but not diagnosed until later, and at different ages, but it is estimated at least 1.5 million individuals have an ASD in the United States (CDC 2007). The CDC and the ADDM network use the age of eight as their point of reference, as does the National Center for Health Statistics (NCHS). According to Rudy (2014), the incidence rate in the United States grew by over 800% from 1992 to 2003. In 1992, an estimated 15,580 individuals between the ages of 6 and 22 had autism. In 2003, the number grew to 163,773 individuals with autism.

Sex

According to the CDC (2012) statistics covering the year 2008 from the ADDM network, prevalence rates among boys were significantly higher (about five times more common) than among girls, with 1 in 54 boys (18.4 per 1,000) estimated to have an ASD, and 1 in 252 girls (4 per 1,000) estimated to have an ASD. Other studies have consistently found ASDs to be more prevalent among boys (Rutter and Lockyer 1967; Baird, Charman, Baron-Cohen et al. 2000; Chakrabarti and Fombonne 2001), and this fact alone may have an impact on employment among ASD individuals. ASDs have always been noted to be higher among boys than girls, which has puzzled the scientific community, and may point to a genetic component. Studies in genetics are a recent addition to the research among the ASD population.

Sex is a significant factor in employment outcomes. Women are employed in less prestigious jobs than men, occupational roles are linked with sex and gender roles which limits choices among women concerning employment, and women have consistently had lower earnings than men in the United States (Lindsey 1997). Historically, men have been employed at a higher rate than women, and the same still holds true; in 2012, 57.7% of women participated in the labor force while 70.2% of men participated in the labor force (U.S. Bureau of Labor Statistics 2014).

Race/Ethnicity

ASDs are found in every racial and ethnic group (CDC 2012). In a study conducted by Yeargin-Allsopp, Rice, Karapurkar et al. (2003) on 987 children with an

ASD in Atlanta, Georgia, prevalence was found to be similar among blacks and whites, with 3.4 per 1,000 among both groups, and 2.9 among other groups (data from 1996). However, according to the CDC (2012), white children have a significantly higher estimated prevalence rate than other groups. Overall, estimated prevalence rates were 12.0 per 1,000 among non-Hispanic white children, 10.2 per 1,000 among non-Hispanic black children, and 7.9 per 1,000 among Hispanic children. There is some variation among the sites for sex and race/ethnicity prevalence; the findings here are listed as an overall finding.

Race is a barrier to employment due to systematic discrimination (King 1988). Historically, whites have participated in the labor force more than any other race in the United States. According to the U.S. Census Bureau Current Population Report (2003), 12% of blacks were employed compared to 72% of non-Hispanic whites in 2002 (McKinnon 2003). Although non-Hispanic white participation in the labor force has increased, black participation in the labor force has not. In 2013, blacks made up 12% of the labor force compared to 79% of whites (U.S. Department of Labor 2014).

Social Class

ASDs occur in every racial, ethnic, and socioeconomic group, according to the CDC (2012). The early descriptive studies found more ASD children among parents from a higher social class (Creek and Ini 1960; Lotter 1966; Treffert 1970). However, later studies concluded that the preponderance of ASDs among higher social class were biased due to greater access to diagnostic and treatment centers in this population (Schopler, Andrews and Strupp 1979; Wing 1980; Tsai, Stewart, Faust et al. 1982). Studies conducted in the 1990s (Fombonne, du Mazaubrun, Cans et al. 1992; Arvidsson, Danielsson, Forsberg et al. 1997) did not show an association between higher social class and ASDs, suggesting it is a uniform condition among the social classes.

Social class presents and/or restricts opportunities (or life chances) (Weber 1978), including employment opportunities. Those of lower class hold less prestigious jobs earning less than those of higher classes, have less power compared to those of higher classes, and own less property; in general they have less resources available to them than those in higher social classes.

ASDs as a Disability

The fact that ASDs influence behavior, communication, and social integration necessitates that ASDs be considered a disability, as does its inclusion in the DSM. Individuals with disabilities are afforded certain federal rights; however, before civil laws were passed individuals with disabilities were placed in institutions and separate schools. Disabled individuals were mostly treated like second-class citizens leading to stigma; however, civil laws mandated equal opportunities for employment, accessibility, and nondiscrimination. Though this may have led to a decrease in stigma over time, the civil laws have not eliminated stigma among the disabled population.

The first civil rights law protecting the rights of individuals with disabilities on the federal level was the Rehabilitation Act (RA) of 1973 (P.L. 93-112), which defined disability very broadly as “an impairment that significantly limits one or more major life activities,” such as difficulties in learning, seeing, and walking. Nondiscriminatory practices are addressed in Section 501 which requires federal agencies in the executive branch to practice nondiscrimination in employment; Section 503 requires contractors and/or subcontractors dealing with the federal government with contracts more than

$10,000 to practice nondiscrimination in employment, and Section 504 requires programs receiving federal financial assistance to not discriminate against disabled individuals (this includes public schools). Independent living opportunities for disabled individuals were legislated with the Rehabilitation Act Amendment of 1986, P.L. 99-506 (Section 702b). Independent living is defined as ". . . the ability of an individual with handicaps [*sic*] to live independently and function within his family and community, and, if appropriate, secure and maintain appropriate employment."

Full civil rights to all individuals with disabilities were granted in the American with Disabilities Act (ADA) of 1990 (P.L. 101-336, 42 U.S.C. § 12101). Discrimination was prohibited in employment in the public and private sector, public accommodation, transportation, state and local government services and telecommunications with the ADA. The ADA also prohibited discrimination of students with disabilities granting the right of access to educational programs and services, regardless of federal funding. The definition of disability according to the ADA states "(i) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (ii) a record of such an impairment; or (iii) being regarded as having such an impairment" (ADA, 42 U.S.C. § 12101(2)).

Further legislation was enacted to provide support to individuals with disabilities to consider their interests and abilities while attaining and maintaining employment outcomes, focusing on all individuals with the ability to be employed, regardless of the severity of the disability. Individuals with disabilities are assisted in attaining and maintaining employment by rehabilitation programs.

ASDs and Employment Outcomes

Research has shown that individuals with ASDs have poor employment outcomes. In a study conducted by Burt, Fuller, and Lewis (1991), it was found that success in the employment arena was associated with appropriate communication, interpersonal skills, gradual fading of supervision, and family support. This study is one of the early studies on employment on ASDs, and only had four adults, ages ranging from 21 to 29.

Marder, Cardoso, and Wagner (2003) analyzed data from the National Longitudinal Transition Study -2 with 11,000 students aged 13 to 16 as of December 1, 2000. Findings indicated that students with autism, multiple disabilities, mental retardation, or deaf-blindness were 30% more likely to be employed in work-study jobs than those with learning disabilities and impaired speech. Thus, these students were not employed in traditional competitive employment, but rather at school or at a job the school found. One-third of adolescents with multiple disabilities, deaf-blindness, orthopedic impairments, mental retardation, and visual impairments were employed; however, during the same one-year period, only 14.5% of adolescents with autism were employed. Also in 2003, a longitudinal study conducted by the U.S. Department of Education and Rehabilitative Services (Hayward and Schmidt-Davis 2003) revealed that Vocational Rehabilitation Services (VRS) deemed 65% of applicants classified with significant or most significant disabilities ineligible for services. VRS classifies individuals with ASDs as having significant or most significant disabilities.

In 2004, Hurlbutt and Chalmers found that gaining and maintaining employment were difficult among the ASD population. This study interviewed six adults with

Asperger's Syndrome (a high functioning ASD) aged 25 to 56. Each individual expressed difficulty in finding a job that matched their ability levels, and maintaining employment was the biggest problem for each individual.

Shattuck, Narendorf, Cooper et al. (2012) also found poor employment outcomes associated with individuals with ASDs, especially in the first two years after graduating high school. Using nationally representative data, the researchers found that more than 50% of ASD youths that had left high school in the past two years had not participated in employment or continuing education. Additionally, only 55.1% of ASD youths had been employed during the first six years after graduating high school. ASD youths had the lowest rate of employment when compared with youths having speech/language impairment, learning disability, and mental retardation. Findings also concluded that coming from lower income families and having greater functional impairments increase the risk for poor outcomes of employment.

ASD and Comorbidity

Comorbidity studies are emerging in importance in the scientific community, with the premise that understanding how comorbidity arises could help us understand the development of psychopathology, along with the etiology, course, and treatment of psychiatric disorders (Angold, Costello, and Erkanli 1999). However, comorbidity can also have an impact on daily functioning, which would in turn influence social involvement such as employment. According to McAlpine and Warner (2002), for respondents to the 1994-1994 National Health Interview Survey, 59% of individuals with a physical disability were employed, compared to 36% of individuals with both physical and mental disabilities.

Psychiatric comorbidities such as phobias, depression, and other childhood disorders have been described in studies concerning ASDs for almost 30 years (Matson and Nebel-Schwalm 2007). Medical conditions are also observed with high frequency among the ASD population, including about 30% having seizure disorders, 2-5% having fragile X syndrome, and 1-3% having tuberous sclerosis (Tsai 1996). Gillberg and Billstedt's (2000) research found that medical conditions, psychiatric disorders, and behavioral and motor control symptoms are associated with autism and Asperger syndrome. They believe that comorbidity should be expected in ASDs. The CDC (2012) concludes that 83% of the ASD population has at least one comorbid disorder.

Mood disorders are major depression and bipolar disorder, and both can be debilitating (Matson and Nebel-Schwalm 2007). Depression is diagnosed in 2% of autistic children studied (Ghaziuddin, Tsai, and Ghaziuddin 1992). Depression is the most frequent form of comorbid psychopathology among individuals with ASDs (ibid.). Comorbidity rates among children with Asperger Syndrome are as high as 30% (Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin 1998; Wing 1981). Bipolar disorders have also been found in children with ASDs (Gillberg 1985; Realmuto and August 1991) but research lacks reliable and valid methods of assessing bipolar disorder in children. More research needs to be conducted in this area.

Matson and Love (1990) matched the intensity of fears and phobias of autistic children with normal same age peers, the first systematic group study of phobias. Autistic children's phobias did not show much overlap with the normal matched peers, and autistic children were found to be more fearful of thunderstorms, dark places, dark rooms, dark closets, going to bed in the dark, closed places and large crowds.

In 2005, Evans, Canavera, Kleinpeter et al. studied 25 ASD children, 43 children with Down syndrome, 45 children matched on mental age, and 37 chronologically matched normal developing peers in a replicative and extended study of the 1990 Matson and Love study. Similar findings were noticed, with ASD children showing medical, animal, and situation phobias to be more common, which are a different set of fears and phobias than the other children.

Anxiety disorders, such as obsessive-compulsive disorder (OCD) overlap with ASD symptoms, and are hard to separate from the ASD (Matson and Nebel-Schwalm 2007). However, in a 1967 study, Rutter, Greenfield, and Lockyer reported that 37% of 63 children had obsessive traits, and 60% had anxiety and fear. Simons (1974) observed compulsive behavior in every child diagnosed with autism. Ando and Yoshimura (1979) reported among 47 autistic children, 68% had stereotyped behavior, and in a follow-up study of adult males, Rumsey, Rapoport, and Sceery (1985) found that 86% still demonstrated stereotyped, compulsive behaviors. Obsessive-compulsive disorders were also found in the ASD population by Tsai (1992) and McDougle, Price, and Goodman (1990). Other disorders found include schizophrenia (Petty, Ornitz, Michelman et al. 1984; Clarke, Littlejohns, Gorbett et al. 1988; Volkmar and Cohen 1991), and Tourette syndrome (Barabas and Matthews, 1983; Comings and Comings, 1991; Realmuto and Main 1982; Sverd, Montero, and Gurevich 1993).

Ghaziuddin and Zafar (2008) conducted a study at the University of Michigan medical center, with 28 subjects referred over a five-year period. Twenty-one of the 28 subjects had a comorbid disorder, with the most common diagnosis being depression and other mood disorders (*n* = 14). Anxiety disorders (*n* = 6) were the second most diagnosed disorder. These findings were consistent with studies of comorbidity in children (Ghaziuddin, Weidmer-Mikhail and Ghaziuddin 1998, Gillberg and Bilstedt 2000).

Lugnegard, Hallerback, and Gillberg (2011) investigated psychiatric comorbidity among adults (26 men and 28 women) with Asperger syndrome (mean age 27 years) and found that 70% had at least one major depression episode, and 50% had experienced recurrent depressive episodes. Anxiety disorders were also found to be present in about 50% of the study group; however, psychotic disorders and substance-induced disorders were uncommon.

Rosenberg, Kaufmann, Law et al. (2011) used the IAN online registry to study comorbidity in 4,343 children with ASDs. The most common comorbid diagnoses were ADHD or ADD (38.1%), anxiety disorders (26.2%), depression (11.0%), and bipolar disorder (5.2%). There was no difference in the proportion of comorbidity by sex, and only anxiety was significant for race. Hispanic children were less likely to have anxiety or depression.

Gastrointestinal disorders, feeding issues, food selectivity, and constipation among the ASD population have been debated. Studies have reported a 9-70% frequency of gastrointestinal problems in children with ASDs (Black, Kaye, and Jick 2002; Molloy and Manning-Courtney 2003; Valicenti-McDermott, McVicar, Rapin et al. 2006). More research needs to be conducted in this area.

Sleep disorders in the ASD population have been estimated to be around 44-83 %, yet there has been limited research in this area (Richdale 1999). Williams, Sears, and Allard (2004) studied 210 children with autism and found that difficulty in falling asleep was reported by over half of the respondents, consistent with other studies. Taira, Takase, and Sasaki (1998) surveyed 88 children with autism, and found that 56 children had sleep disorders, with the most common problem being difficulty falling asleep. It is important to note that clinicians are reluctant to make additional psychiatric diagnoses in lower functioning autistic individuals as they are not able to provide interviews or use self-report scales (Tsai 1994).

ASDs and Social Support

Social support is the availability or existence of people who care about, love, and value us, and upon whom we can rely (Sarason, Levine, Basham et al. 1983). According to Pottie et al. (2009), social support enhances psychological and physical well-being. Social support encompasses psychological and material resources, and those who receive social support are healthier than those with less supportive social contacts (Mitchell, Billings, and Moos 1982; Broadhead, Kaplan, James et al. 1983; Leavy, 1983). According to House (1987), social support acts as a buffer to stress, reduces morbidity and mortality, and lessens exposure to psychosocial stress.

Lasgaard, Nielsen, Eriksen et al. (2010) conducted a study on 39 adolescent males with ASDs and found that perceived social support was negatively associated with loneliness. Renty and Roeyers (2006) studied 58 high functioning adults and found that social support has a positive effect on quality of life. Some examples of social support are financial aid, care giving, living conditions, and job training.

Müller, Schuler, and Yates (2008) asked 18 individuals with ASDs about social challenges and supports. Common experiences were found among the group. These include a marked sense of social isolation, difficulty with social interaction, communication and intimacy challenges, a desire to be involved in the community and contribute to the community, and a desire for greater self-awareness. The ASD individuals in the study recommended external social supports such as shared interest activities, small groups, and highly structured social activities would be helpful, as well as communication supports and support in controlling anxiety. Social support can be beneficial to these individuals by acting as a buffer to stress (House 1987) and alleviating loneliness (Lasgaard, Nielsen, Ericksen et al. 2010). Examples of social support that may help ASD individuals accomplish goals could be in the area of financial support, care giving or transportation, and job training.

Social support is also associated with employment among the ASD population. In a study conducted by Burt, Fuller, and Lewis (1991), it was found that success in the employment arena was associated with appropriate communication, interpersonal skills, gradual fading of supervision, and family support.

ASDs and Education

According to Durkheim (1956), education has two main roles. Education socializes the young according to society norms, preparing them for adult roles. Education also is factor for selection into occupation and is based on achievement of the individual. Individuals that are well educated are more likely to have higher income (with less hardship economically), fulfilling jobs that are rewarding to the individual, and a greater sense of control concerning their life and health (Ross and Chia-ling Wu 1995).

Laws passed in the 1970s and 1980s also impacted the education of individuals with disabilities. Federal laws mandated special education services, and incorporated transition services to help adolescents with disabilities to transition from school to adult life.

The Education for All Handicapped Children Act (20 U.S.C. § 1400 *et seq*.), PL 94-142 was passed in 1975, focusing on educational rights for students with disabilities; specifically that students with disabilities were granted a “free appropriate public education” (FAPE). The Individualized Education Plan (IEP) was established to accomplish this goal. IEPs can include services such as speech therapy, audiological and psychological services, physical, recreational, and occupational therapies, counseling services (including rehabilitation counseling and parent counseling), training, and transportation. These and other services are incorporated into the IEP to ensure that an appropriate education in the least restrictive environment (LRE) is procured. Amendments extended these services to children ages birth to five years and their families in 1986, incorporating an Early Intervention Plan or Individualized Family Service Plan (IFSP). The Individuals with Disabilities Education Act (1990) (IDEA, P.L. 101-476) renamed P.L. 94-142, and required IEPs to include transition services for transition aged students (by age 16); autism and Traumatic Brain Injury (TBI) were added to the categories of disabilities served, and more emphasis was placed on the LRE. Other laws enacted or amended were IDEA, P.L. 101-476, 20 U.S.C. Chapter 33, Section 1401(a)(19); The No Child Left Behind (NCLB, 20 U.S.C. 70 § 6301 *et seq*., 2002); and The Individuals with Disabilities Education Improvement Act (IDEIA) in 2004. These laws focused on yearly progress made, continuing transition services to adulthood, and changed the focus of the programs to results-oriented. The goal of these acts and laws was to help disadvantaged and disabled children to be able to function in social life after leaving high school.

Stigma Theory

Individuals with ASDs exhibit different behaviors than the normal population, and thus are looked differently upon by society, or stigmatized. Goffman (1963) defined stigma as ‘‘an attribute that is significantly discrediting” and states that the stigmatized individual is reduced “from a whole and usual person to a tainted, discounted one” (ibid: 3). Goffman states that people who are stigmatized have an “undesirable difference” that serves to discredit people. People with physical deformities, suffering from mental illness or those with socially deviant behavior are seen as stigmatized, making it harder for these individuals to participate in social life, including employment. Goffman saw stigma as embedded in a “language of relationships” (ibid: 3). Jones et al. (1984) also described stigma as a relational process, meaning that deviance is defined by the social environment which also provides a way to express devaluation of the individual. Crocker, Major, and Steele (1998) state that stigma can occur when an individual possesses an attribute that is often objective, and proposes that stigma is a “devaluing social identity” (ibid: 505) as did Goffman. Furthermore, stigma occurs within a social context which defines the objective attribute as a devalued attribute. Link and Phelan (2001) state that stigma is a broad concept linking interrelated components of stigma. Labeling, stereotyping, and cognitive separation are social processes occurring within society (or the environment) with effects being observed in the individual. First, differences among people are distinguished and labeled. Next, the labeled person is linked to undesirable characteristics causing negative stereotypes stemming from cultural beliefs that are dominant. Third, persons that are labeled are placed in distinct categories to separate “us” from “them” (emotional reactions were added as a component in Link, Yang, Phelan et al. in 2004).

Fourth, status loss and discrimination are also included as components by Link and Phelan (2001) leading to unequal outcomes, and thus the stigma process depends on social, economic, and political power. This power allows differentness to be identified, stereotypes constructed, separation into categories from labeling, and the disapproval, rejection, exclusion, and discrimination to be executed. Stigma appears to be universal (ibid.) but the meanings, practices and outcomes of stigma vary across cultures. Stigma is seen as a negative attribute, and people who are seen as different are negatively valued in society, which can cause some groups to be devalued leading to social inequality (Parker and Aggleton 2003). Thus, people who are stigmatized are discredited, devalued, and different, which makes it harder for the stigmatized individual to participate in normal society. For individuals with mental illness, stigma is a proximate and distal cause of employment inequality resulting in direct and indirect discrimination in employment (Stuart 2006). Since ASDs are considered a mental illness, which is stigmatized, and individuals with ASDs have peculiarities in behavior, they are seen as different, which leads to being devalued and discredited. This devaluation and discrediting compounds the already difficult time individuals with ASDs have with social interaction.

The different types of ASDs have different types of impairments and characteristics, some more severe than others, and the severity of the ASD also varies among ASD individuals. ASD individuals with comorbid disorders will exhibit more peculiarities in behavior, thus acquiring more stigmas. Thus, the stigma applied to any accompanying comorbidity may play a role between the ASD population and employment.

Social support is necessary for those with disabilities to lead a productive life and is also important in lessening the effects of mental illness and stigma, and thus may play a mediating role in employment.

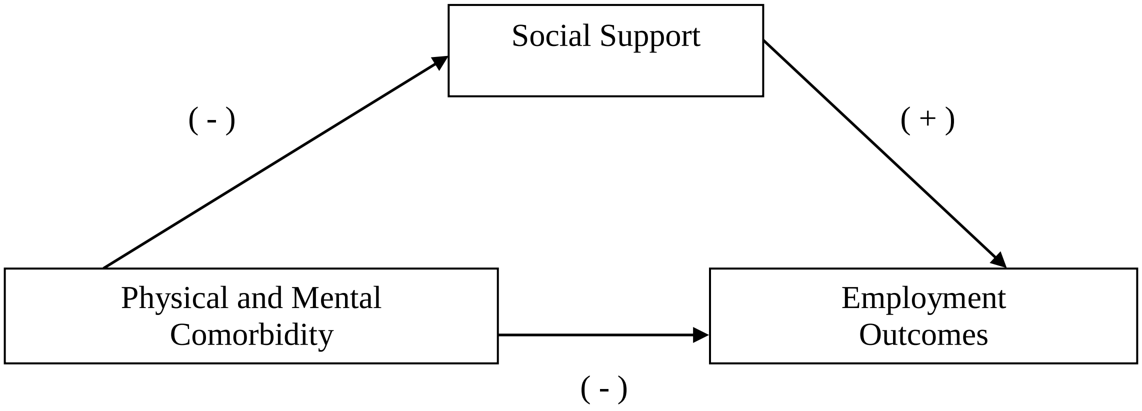

Figure 1. Conceptual Diagram of Hypotheses

Hypotheses

Empirically, it has been found that those with ASDs are the least likely of those with disabilities to gain employment (Cameto et al. 2003). Theoretically, it can be argued that the stigma applied to ASDs and other comorbidities impact ASD employment, and the more physical and/or mental disorders one has, the more stigma is applied. This would have ramifications for employment; for instance, one might be willing to hire a person with autism, but one may be afraid the co-existing obsessive-compulsive disorder (for example) may disrupt the work or the work environment; thus more stigma would be applied, and the person may not be hired, may work less hours, or may not be able to retain employment. It is important to look at mental and physical comorbidities separately. Mental disorders are more stigmatized than physical comorbidities (Goffman 1963), thus having more mental comorbidities would result in having more stigma than having more physical comorbidities. Stigma is a proximate and distal cause of employment inequality for those with mental disabilities, resulting in direct and indirect discrimination in employment (Stuart 2006).

Based upon review of the literature, there is an empirical and theoretical basis that comorbidity is a factor in employment. To work, one must have a certain level of functioning. In a study conducted by Cook, McGuire and Miranda (2007) on 1,273 individuals with severe mental illness, lower earnings were found among individuals with comorbidity, and individuals with comorbidities were less likely to work competitively. They also found that individuals with physical comorbidities were less likely to work competitively, had lower earnings, and worked less hours. Braden, Zhang, Zimmerman et al. (2008) used data from the Healthcare and Community Survey (*N* = 5,328) and found that individuals with mental illness and chronic pain reported that their ability to work was limited.

Given the nature of ASDs, social support variables commonly used in employment research may not be applicable to ASD individuals. Individuals with ASDs have special needs and interests, and the fact that they have social, behavioral, and communication deficits may mean that social support is even more necessary among this population. Thus, this research uses living arrangements and financial support as measures of social support.

The purpose of this study is to determine what role, if any, comorbidity and social support play in the relationship between adults with ASDs and employment. Given that comorbidity is found among the majority of the ASD population, it is used as the primary predictor variable of employment. Social support is also used as a predictor variable, and is examined as a potential mediating factor on the impact comorbidity may have on employment among the ASD population. To conduct this research, four hypotheses are presented:

Hypothesis 1: Comorbidity has a negative effect on employment. A greater number of physical or mental comorbidities decrease the likelihood of employment.

Hypothesis 2: Social support is positively associated with employment; social support increases the likelihood of employment.

Hypothesis 3: Social support mediates the negative association of comorbidity on employment.

Hypothesis 4: Those with lower status as indicated by less education, being non-white or female will have a lower likelihood of employment.

CHAPTER THREE

METHODOLOGY

This chapter discusses the dataset, measures, and analytic procedures used in this study. The study is designed to answer two central research questions. The first question is: does number and type of comorbidity play a role in the relationship between adults with ASDs and employment? The second question is: does social support impact the relationship between comorbidity and employment?

Data

To research this question, this study utilizes de-identified data obtained from the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute and Johns Hopkins Medicine - Baltimore, sponsored by the Autism Speaks Foundation; version dated April 18, 2014. IAN is the nation’s largest online autism research effort, and is a partnership of the Kennedy Krieger Institute, the Simons Foundation, Autism Speaks, and the National Institute of Mental Health (NIMH). (This information can be found at www.ianproject.org.) IAN was established in 2006 by the Kennedy Krieger Institute, and the IAN Community and IAN Research were created to accomplish the goal of facilitating research leading to advancements in treating and understanding ASDs. IAN is funded by Autism Speaks and the Simons Foundation, along with a grant from the National Institutes of Health (NIH). Data collection started in 2007.

Research is conducted through IAN Research, a research study under the auspices of the John Hopkins Medicine IRB, with Paul H. Lipkin, M.D. as the Principal Investigator. IAN is an online community set up to help accelerate research on ASDs, bringing researchers and the public together. IAN Research is an ongoing, extensive cross-sectional and longitudinal database and research registry. Online questionnaires are completed by individuals with ASDs, their families, and guardians of individuals with ASDs throughout the world. Data is gathered on individuals with ASDs, siblings of individuals with ASDs, and parents of individuals with ASDs. Some of the online questionnaires are standardized; an example is the Social Responsiveness Scale. Other topics, such as pregnancy, parental depression, and treatments are developed in partnership with experts in the subject matter. ASD respondents are asked what aspects of autism are important for autism research, and questionnaires are added to the protocol based on the priorities expressed by researchers and the ASD community. Thus, the ASD community and the scientific community influence the direction of the research.

IAN Research was launched in April 2007, and has registered over 45,000 participants, which includes 17,000 individuals with ASDs along with their parents and siblings. Additional information on the research can be found at www.iancommunity.org.

The current study is interested in employment among individuals with an ASD, thus uses a limited sample consisting of adults with an ASD who filled out the online IAN Adult with ASD Questionnaire: Self-report (Appendix A). The Basic Family Information - Demographics questionnaire will also be used to gather socioeconomic data such as sex and race (Appendix B).

The adult questionnaires (self-reported and those answered by a legal representative) were first published on August 24, 2009 and center on ASD diagnosis, strengths, abilities, special interests, daily living (such as employment and housing arrangements), and past history of participation in ASD-related research. The questionnaires also solicit suggestions about potential topics for IAN's next survey for adults with ASD. However, this study is only interested in the work history of those ASD individuals who were capable of answering the questionnaires, as these adults are showing more functionality, thus only the IAN Adult with ASD Questionnaire: Self-report sample is used. There were a total of 255 independent adult respondents who completed the online questionnaire between April 8, 2009 and February 18, 2014.After adjusting for missing information among the variables, the self-report sample was reduced to 222 respondents. There are 50 questions on the self-report questionnaire.

Variable Measurement

Dependent Variable

The outcome (or dependent) variable of this study is employment, a dichotomous variable. Employment is measured by employment status of the individual; employed or non-employed. Part-time and full-time employment was not assessed. To assess employment, the self-report adult questionnaire asks: “Do you currently have paid employment?” Response options include “Yes” or “No”.

Independent Variables

The primary predictor variable in this study is comorbidity, a continuous variable measured by number of physical disabilities and number of mental disabilities. Comorbidity is common among individuals with ASDs (Tsai 1996; Gillberg & Billstedt

2000, CDC 2012). To ascertain comorbidity, there are two questions asked on the independent self-report adult questionnaire. The first question assesses physical disabilities. The question asked is “Do you suffer from any of the following? Check yes or no for each response.” Response options include: “Gastrointestinal issues (such as chronic diarrhea, constipation, nausea, vomiting, acid reflux, etc.),” “Allergies,” “Sleep issues (such as problems going or staying asleep),” and “Skin conditions (such as psoriasis or eczema).” The response options for this question are all physical disabilities. The second question asked is “Have you been diagnosed with any of the following conditions by a professional? Check yes or no for each response.” Response options are: “A seizure disorder or epilepsy,” “Asthma,” “Diabetes,” “Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD),” “Oppositional Defiant Disorder (ODD),” “Obsessive Compulsive Disorder (OCD),” “Anxiety (such as social phobia, generalized anxiety disorder, panic disorder, or some other kind of anxiety),” “Depression (such as major depressive disorder, seasonal affective disorder, postpartum depression, or some other kind of depression),” “Bipolar Disorder,” “Schizophrenia,” and “Other.” Asthma, seizure disorders, and diabetes were coded as physical ailments.

Social support is also an independent variable, is categorical, and may be a mediating or suppressor variable. Social support includes questions concerning living arrangements and financial support; living arrangement is a nominal variable, financial support is an ordinal variable. Two questions are asked to determine living arrangements. The first question is “Do you live with any other people?” Responses are “No” and “Yes.” This question is used to determine if the person lives alone, and is included in the living arrangements assessment. The second question concerning living arrangements asks: “With whom do you live? Check all that apply.” Options include: “With a spouse or other life partner,” “With my children,” “With housemates or friends that I got to choose,” “With housemates I didn't get to choose,” “With my parents,” “With one or more siblings.” The responses to these two questions were collapsed into the following categories: “Live alone”; “Live with parents, siblings, or relatives”; “Live with spouse, partner, and/or children”; “Live with housemates” (either chosen or not chosen).

Financial support is measured on the self-report adult questionnaire by the question: “How much, if any, do you rely on your extended family (such as parents and siblings) for financial support?” Response options are “My family does not provide any financial support for me at all.” “My family provides less than half of my financial support. They help me financially sometimes.” “My family provides about half of my financial support.” “My family provides more than half (but not all) of my financial support.” “My family provides all of my financial support.”

Sociodemographic Variables

In addition to the independent variables of comorbidity (number and type of comorbidity) and social support, I examine the relationship between sex, education, and race influencing the likelihood of employment. Additionally, age will be used in this study as a control variable.

Sex is a nominal variable, and is ascertained by the respondent or the legal representative filling in sex, “Male” or “Female”.

Education is an ordinal variable. On the self-report adult questionnaire, education is measured by the question “What is the highest level of education you have completed?” Response options are: “Less than high school,” “High school certificate of completion (special education alternative to diploma),” “High school graduate or equivalent (GED),” “Trade or vocational school (certificate or license but no degree),” “Some college but no degree,” “Associate's degree in vocational or technical program,” “Associate’s degree in academic program,” “Bachelor's degree,” “Master's degree,” “Ph.D. or Professional degree,” “Other.” After running frequencies, these were collapsed into four categories: “Less than high school and other”; “High school graduate or equivalent (GED), trade or vocational school (certificate or license but no degree)”; “Some college but no degree, Associate’s degree in vocational or technical program, Associate’s degree in academic program”; Bachelor’s degree, Master’s degree, Ph.D. or Professional degree.”

Race, a nominal variable, is gathered from the Basic Family Information - Demographics questionnaire (Appendix B). The respondent is asked to check all that apply under the heading of Race: “White,” “Black/African American,” “Native Hawaiian or Pacific Islander,” “Asian,” “American Indian or Alaskan Native,” “Other,” and “Unknown.” The respondent was also asked about their ethnicity; options were “Hispanic” or “Latino” or “Not Hispanic or Latino.” Due to the low frequency of different races/ethnicities, and the fact that a person could check more than one race, these categories were collapsed into “Non-Hispanic White” and “Other.” If anything other than Non-Hispanic White was checked, the response was coded as “other.”

Age is ascertained from a written-in answer under the heading of Age (age at time of participation), and is a ratio variable. For easier interpretation, age was collapsed into five categories: “18 - 25”; “25-29”; “30-39”; “40-49”; and “50 and above.”

Analytic Procedures

This study utilizes bivariate and multivariate techniques. Frequencies, t-tests, and Chi-square tests are performed, and then nested logistic regression. Given the non-linear nature of the dependent variable (employment), formal tests of mediation are not possible. Thus, I will examine how the coefficients change for the number and type of comorbidities and social support using nested logistic regression.

The first model addresses Hypothesis 1 by regressing comorbidity (measured by number of physical comorbidities and number of mental comorbidities) on employment. In the second model, which addresses Hypotheses 2, social support (measured by living conditions and financial support) is regressed on employment. The third model, addressing Hypothesis 3, examines the mediating effect of social support on the association between number and type of comorbidity by examining changes in the coefficient for these variables. The fourth model addresses Hypothesis 4 and adds sociodemographic variables of education, sex and race, and includes a control variable of age to examine if those with lower status (such as female, non-white and lower education) have a lower likelihood of employment. Significant results in changes in coefficients in these models will provide support for the hypotheses. Logistic regression analyses are conducted using SPSS (version 20) software package.

CHAPTER FOUR

RESULTS

Descriptives and Bivariate Testing

Table 1 presents descriptive statistics for all variables on percent not employed, percent employed, and total sample. Bivariate tests were performed on the sample. Chi-square testing was performed on categorical variables, and t-tests were performed on continuous variables to test for difference between employed and non-employed ASD individuals. The total sample size is 222; of the sample, 53.2% (*n* = 118) were non-employed, and 46.8% (*n* = 104) were employed.

Comorbidity is a continuous predictor variable and it is divided into two categories: number of physical comorbidities and number of mental comorbidities. The mean number of physical comorbidities is 2.89, with most people having 3 numbers of physical comorbidities. Additionally, the mean number of mental comorbidities is 2.51, with most people having 2 numbers of mental comorbidities. Although the IAN questionnaire does ask detailed questions about types of comorbidities, I create a summed measure of number of physical and mental comorbidities. This is done because it would be difficult to compare each disability separately for employment, since most respondents have more than one physical and/or mental disability. Also, given the number of different types of comorbidities it would be difficult to interpret the results in a meaningful way. Cell size is also limited in examining each type of comorbidity separately. However, I do provide descriptive statistics on the different types of comorbidities. Only 10.4% of the total sample reported no mental comorbidities and 4.1% of the total sample reported no physical comorbidities. Examining the different types of physical comorbidities I find that 14.4% reported gastrointestinal issues; 22.5% reported allergies; 25.2% reported sleep issues (the most reported physical ailment); 18.5% reported skin conditions; 11.3% reported having seizures or epilepsy; 3.6% reported having asthma; and 0.5% reported having diabetes (only one person reported having diabetes). Examining the different types of mental comorbidities I find that 16.2% reported having Attention Deficit Disorder and Attention Deficit Hyperactivity Disorder (ADD or ADHD); 25.2% reported having Oppositional Defiant Disorder(ODD) which was the most reported mental disability; 21.6% reported Obsessive-Compulsive Disorder (OCD); 14.9% reported having anxiety; 6.8% reported having depression; 3.6% reported being bipolar; and 0.9% reported having schizophrenia (the least reported mental ailment).

The social support variable is also divided into two categories; living arrangements and financial support from family. Examining living conditions for the total sample, 22.5% of respondents live alone; 27.9% live with parents or relatives other than spouse and children; 40.1% live with a spouse and/or children (the majority of the sample); and 9.5% live with housemates. Examining financial support for the total sample, 51.4% reported receiving no financial support from their family; 16.2% reported receiving less than half of their financial support from their family; 7.2% reported receiving about half of their financial support from their family; 12.6% reported receiving more than half but not all of their financial support from their family, and 12.6% reported receiving all their financial support from their family.

The sociodemographic variables in this study include sex, education, race, and age. Examining sex for the total sample, it was found that 35.6% of the sample was male, 64.4% were female. This sample is not representative of the overall ASD population as far as sex is concerned, as the prevalence rate for males is four to five times the rate of females (CDC 2012). The education level among the total sample is as follows: 4.5% reported less than a high school education; 18.5% reported having a high school degree or equivalent; 33.3% reported having an Associate's or Technical degree; and 43.7% reported having a Bachelor's degree or higher. This is a highly educated group compared to the general public. The statistics for the general public aged 25 and over show that in 2010, 31.7% of adults aged 25 and over had a Bachelor's degree or higher (U.S. Department of Education 2011). Examining race for the total sample, 82.9% reported their race as being non-Hispanic white, and 17.1% reported being another race or being of two or more races. Overall, the age of the ASD individuals in this data set fell between 18 and 71. Age categories for the total sample is as follows: 21.2% ranged between the ages of 18 to 25; 11.7% ranged between the ages of 26-29; 20.7% ranged between the ages of 30-39; 22.1% ranged between the ages of 40-49; and 24.3% were aged 50 and above.

Next I looked at differences between employed and non-employed individuals. Employed individuals had an average of 2.63 physical comorbidities, while those who were not employed had an average of 3.14 physical comorbidities. T-tests were utilized to determine whether the differences in physical and mental comorbidity between the employed and not employed are significant. Results indicate that employed individuals had significantly less physical comorbidity than those not employed ($p < 0.01$). As for mental comorbidity, the mean was 2.08 for those that were employed and 2.94 for those not employed. T-tests were also utilized to determine whether this difference is significant and indicate that employed individuals had significantly less mental comorbidities than non-employed individuals ($p < 0.001$).

Additionally, I provide descriptive statistics on the different types of comorbidities by employment. The percentages of physical comorbidities among those that are employed are as follows: 6.7% reported no physical ailments; 19.2% reported gastrointestinal issues; 22.1% reported allergies; 25.0% reported sleep issues; 15.4% reported skin conditions; 7.7% reported seizures/epilepsy; 2.9% reported asthma; and 1.0% reported diabetes. For ease of interpretation and due to data limitations, the disabilities were summed. The percentages of all physical comorbidities of those not employed are as follows: 1.7% had no physical comorbidity; 10.2% had gastrointestinal issues; 22.9% had allergies; 25.4% had sleep issues; 21.2% had skin conditions; 14.4% had seizures/epilepsy; 4.2% had asthma. Diabetes was not found among those not working. Employed individuals were less likely to have severe disorders such as seizures/epilepsy, skin conditions and asthma. Similar levels of sleep issues and allergies were found among the employed and non-employed. There was a higher level of gastrointestinal issues among the employed, and the only person with diabetes was also employed.

Among mental comorbidities I find that of those employed, 10.6% report having no mental disability; 25.0% report having ADD/ADHD; 31.7% report having ODD; 18.3% report having OCD; 9.6% report having anxiety; 3.8% report having depression, no one reported being bipolar, and 1.0% reported being schizophrenic. Of those not employed, 10.2% of ASD individuals reported no mental disability, 8.5% reported having ADD/ADHD, 20.3% reported having ODD (oppositional defiance disorder), 24.6% reported having OCD, 19.5% reported having anxiety, 9.3% reported having depression, 6.8% reported being bipolar, and 0.8% reported having schizophrenia. Higher levels of ADD/ADHD and ODD were found among the employed. Higher levels of OCD, anxiety, depression, and bipolar disorder were found among those non-employed.

Social support is divided into two categories; living arrangements and financial support from family. Initial bivariate testing showed that living arrangements were not a significant factor in employment ($p = 0.157$). Of those who were employed, 26.0% lived alone; 21.2% lived with parents, siblings, or relatives; 44.2% lived with their spouse, partner, and/or children; and 8.6% lived with housemates. Those who lived with their spouse made up the bulk of those employed. Of those who were not employed, 19.5% lived alone, 33.9% lived with parents, siblings, or relatives, 36.4% lived with their spouse, partner, and/or children and 10.2% lived with housemates.

Financial support from family, however, was found to be a significant factor in employment ($p < 0.01$). Of those working, 60.6% received no financial support from their family; 18.3% received less than half of their financial support from their family; 4.8% received about half of their financial support from their family; 11.5% received more than half of their financial support from their family; and 4.8% received all their financial support from their family. The majority of those working received no financial support from their family. Of those not working, 43.2% received no financial support from their family; 14.4% received less than half of their financial support from their family; 9.3% received about half of their financial support from their family; 13.6% received more than half of their financial support from their family; and 19.5% received all their financial support from their family. The majority of individuals not employed received no financial support from their family. In general, less financial support equaled less employment.

Chi-square tests were also performed on the sociodemographic variables of age, race, sex, and education. Age, sex, and race were not associated with employment; however, education was significantly associated with employment. Of the adults who are employed, 17.3% were ages 18-25; 9.6% were 26-29; 25.0% were 30-39; 23.1% were 40-49; and 25.0% were 50 and above. As mentioned, age was not found to be a significant predictor of employment ($p = 0.410$); however, those in the 30-39 age range and the 50 and above age range were employed at a higher rate than the other age groups at 25.0%. Of the adults who were not employed, 24.6% ranged in ages from 18-25; 13.6% ranged in ages from 26-29; 16.9% ranged in ages from 30-39; 21.2% ranged in ages from 40-49; and 23.7% ranged in ages from 50 and above.

As for sex and employment, of those who are employed, 37.5% were male, and 62.5% were female. Of those not working, 33.9% were males, 66.1% were female. Sex was not found to be a significant predictor of employment ($p = 0.576$) unlike in the general population.

Also unlike findings for the general population, race was not found to be a significant predictor of employment ($p = 0.520$) among individuals with ASDs. Non-Hispanic whites made up 82.9% of the sample, with 17.1% being of another race (coded as other). Of those who are employed, 84.6% were Non-Hispanic white, and 15.4% were of another race. Of those not employed, 81.4% were Non-Hispanic white, and 18.6% were of another race.

Using Chi-square testing, education was found to be a significant factor in employment in ($p < 0.01$). Of those not working, 5.9% did not finish high school; 22.9% had a high school degree or equivalent; 39.8% had some college, and 31.4% had a Bachelor's degree or higher. Of those working, 2.9% had less than a high school degree, 13.5% had a high school degree or equivalent, 26.0% had some college, an Associate's degree or a Technical degree, and 57.7% had a Bachelor's degree or higher. This was the most employed group. Those with less than a high school education, high school education or equivalent, and those with some college were employed less than those with a Bachelor's degree or higher.

Table 1. Percentages and Means for Study Variables among ASD Individuals with and without Employment, Interactive Autism Network Research Database (IANRD), 2014 (*N* = 222)

	Employed		Not Employed	**Total**
Employed	100.00		0	50.00
Comorbidity				
Number of mental comorbidities[1]	2.08 (1.36)	***	2.94 (1.67)	100.00
None	10.6		10.2	10.4
ADD/ADHD	25.0		8.5	16.2
ODD	31.7		20.3	25.7
OCD	18.3		24.6	21.6
Anxiety	9.6		19.5	14.9
Depression	3.8		9.3	6.8
Bipolar	.0		6.8	3.6
Schizophrenia	.0		.8	.9
Other	.0		.0	.0

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Table 1 continued. Percentages and Means for Study Variables among ASD Individuals with and without Employment, Interactive Autism Network Research Database (IANRD), 2014 (N = 222)

	Employed		Not Employed	**Total**
Number of Physical comorbidities¹	2.63 (1.53)	**	3.14 (1.40)	100.00
None	6.7		1.7	4.1
Gastrointestinal issues	19.2		10.2	14.4
Allergies	22.1		22.9	22.5
Sleep issues	25.0		25.4	25.2
Skin Conditions	15.4		21.2	18.5
Seizures or Epilepsy	7.7		14.4	11.3
Asthma	2.9		4.2	3.6
Diabetes	1.0		0.0	.5
Social Support				
Living Arrangements				
Live alone	26.0		19.5	22.5
Live with parents, siblings, or relatives	21.2		33.9	27.9
Live with spouse and/or children	44.2		36.4	40.1
Live with housemates	8.6		10.2	9.5
Financial support from family²		**		
No support	60.6		43.2	51.4
Less than half	18.3		14.4	16.2
About half	4.8		9.3	7.2
More than half	11.5		13.6	12.6
All financial support	4.8		19.5	12.6
Sociodemographics				
Sex				
Male	37.5		33.9	35.6
Female	62.5		66.1	64.4
Education²		**		
Less than high school	2.9		5.9	4.5
High school or equivalent	13.5		22.9	18.5
Some college	26.0		39.8	33.3
Bachelor's degree or higher	57.7		31.4	43.7

Continued on next page

Table 1 continued. Percentages and Means for Study Variables among ASD Individuals with and without Employment, Interactive Autism Network Research Database (IANRD), 2014 (*N* = 222)

	Employed	Not Employed	**Total**
Non-Hispanic White	84.6	81.4	82.9
Other	15.4	18.6	17.1
Age			
18-25	17.3	24.6	21.2
26-29	9.6	13.6	11.7
30-39	25.0	16.9	20.7
40-49	23.1	21.2	22.1
50 +	25.0	23.7	24.3

[1]Significance test indicates if there is a significant difference between employed and non-employed.

[2]Significance test indicates block of variables as a whole has a significant difference between employed and non-employed.

† $p < 0.1$, *$p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Multivariate Testing - Logistic Regression

After running bivariate tests, nested logistic regression was performed on the variables in the data set using four different models. Models are presented in Table 2. The first model regresses the predictor variables of number of physical comorbidities and number of mental comorbidities (comorbidity) on employment. This allows for the examination of the relationship of each type of comorbidity with employment controlling for the other. Next, I examine the predictor variables of social support (living arrangements and financial support) on employment in Model 2. Model 3 regresses both number of physical and number of mental comorbidities and social support on employment to examine how social support mediates the association between number of physical and number of mental comorbidities on employment. The final model includes all predictor variables listed above as well as the sociodemographic variables of sex, education, race, and the control variable of age.

Model 1: Comorbidity and Employment Outcomes

Mental comorbidities were significant in bivariate testing and continued to be significant in multivariate testing. The OR for mental comorbidities is 0.718. Model 1 results indicate that for every additional mental comorbidity, the logged odds of being employed decrease by 28.2% which is statistically significant ($p < 0.001$).

Although bivariate testing showed that having physical comorbidities is a significant factor influencing employment, after controlling for mental comorbidities it is no longer a significant predictor of employment. The odds ratio (OR) for number of physical comorbidities in Model 1 is 0.893, but is not statistically significant ($p = 0.274$). Thus, physical comorbidities were not an important factor after controlling for mental comorbidities.

These results suggest two things. First, it suggests that physical comorbidities and mental comorbidities are positively correlated such that people with more physical comorbidities are also more likely to have more mental comorbidities. Second, it is mental comorbidities, <u>not</u> physical comorbidities that decrease the likelihood of employment among ASD individuals. Additionally, these results partially support Hypothesis 1 indicating a greater number of mental comorbidities decrease the likelihood of employment.

Model 2: Social Support and Employment Outcomes

Social Support in Model 2 is measured by living conditions and financial support. Initial bivariate testing found that living conditions were not statistically significant in predicting employment, and logistic regression also showed no statistical significance in employment whether a person lived alone, with parents, spouses, or housemates

($p = 0.782$, df = 3). The logistic regression results confirm the bivariate tests and find financial support to be a significant predictor of employment. ($p < 0.05$; df = 4). Compared to those that receive all financial support from their family, those that receive no financial support from their family are over six times more likely to be employed (OR = 6.177, $p < 0.01$). Those that receive less than half of financial support from their family are five-and-a-half times more likely to be employed than those receiving all financial support from their family (OR = 5.543, $p < 0.01$). Those that receive about half of their financial support from their family were two times more likely to be employed (OR = 2.098, $p = 0.318$) than those receiving all financial support from their family, although this is not statistically significant. Those receiving more than half, but not all, of their financial support from their family were about three times more likely to be employed than those receiving all their financial support from their family, but the results were not statistically significant, although they were approaching significance (OR = 3.361, $p = 0.054$).

Overall, Model 2 shows that social support is a factor in employment; however, only financial support is significantly associated with employment. Living arrangements showed no statistical significance association with employment outcomes. In general, less financial support is associated with a greater likelihood of employment. This is contradictory to Hypothesis 2, which states that social support would be positively associated with employment, thus increasing the likelihood of employment.

Model 3: Comorbidity, Social Support, and Employment Outcomes

Model 3 includes the comorbidity measures (number of mental and number of physical) as well as social support to examine how social support mediates the association of comorbidities with employment. Number of mental comorbidities continued to be significant in Model 3, with the OR changing from 0.718 ($p < 0.001$) in Model 1 to 0.764 ($p < 0.05$) in Model 3 after social support variables are included. Thus, Model 3 suggests that social support partially mediates the association between mental comorbidity and employment, explaining about 18% of this association. However, social support does not fully mediate mental comorbidity as shown by the still significant odds ratio in Model 3. For every additional mental comorbidity, there is a 23.6% decrease in logged odds of being employed (OR = 0.764, $p < 0.05$). The physical comorbidity variable still was non-significant in employment outcomes, though it did show further mediation after social support is controlled (OR = 0.893 in Model 1, OR = 0.846 in Model 3). As for social support, the overall living arrangements still were not significant in employment outcomes. Additionally, Model 3 demonstrates that financial social support is no longer significant as a block of variables; however, certain aspects of financial support still showed significance. Compared to those who receive all financial support from their family , those who receive no financial support from their family are about five times more likely to be employed (OR = 5.290, $p < 0.01$). Those who receive less than half of their financial support from their family are also about five times more likely to be employed as those who receive all their financial support from their family which is also significant (OR = 4.937, $p < 0.05$). ASD individuals receiving about half of their financial support from their family are not significantly different than those who receive no financial support from their family.

Overall, I found some mediation in Model 3. Including the social support variables accounted for about 18% of the association with comorbidity with employment, though comorbidity still remains a significant predictor of employment. This suggests that those with higher levels of comorbidities have greater financial support from their families, which is negatively associated with employment. Thus, Hypothesis 3, stating that social support would account for the negative association between comorbidity and employment was partially supported. The higher levels of financial support partially accounts for the decreased likelihood of employment with increasing mental comorbidities, though this association remains significant.

Model 4: Comorbidity, Social Support, Sociodemographics (Sex, Race, Education, Age) and Employment Outcomes

The final model (Model 4) addresses Hypothesis 4 by including sociodemographics to Model 3. Including sociodemographics did little to change the association between the independent variable of comorbidity and employment, and also did little to change social support and employment; the coefficients remained virtually unchanged. Mental comorbidity and some aspects of financial support still showed significance in employment outcomes. Additionally, education is significant ($p < 0.05$, df = 3), but not race, age, and sex. Those with less than a high school education were not significantly different in their likelihood of employment than those with a Bachelor's degree or above (OR = 0.317; $p = 0.156$), however, this finding should be interpreted with care given the small numbers of those with less than a high school education ($n = 10$). Those with a high school degree or equivalent had a 66.6% decrease in logged odds of employment over those with at least a Bachelor's degree (OR = 0.334 $p < 0.05$), which is significant. Those with some college had a 62.2% decrease in being employed compared to those with a Bachelor's degree or above (OR = 0.378, $p < 0.01$), which is also statistically significant.

Examining social support and comorbidity, I continue to find a significant association between mental comorbidity and employment (OR = 0.762, $p < 0.05$). For every additional mental comorbidity, there is a 23.8% decrease in the odds of being employed. Additionally, financial support continued to have some aspects that were significant, but was no longer significant overall ($p = 0.070$, df = 4), though the model does suggest some suppression after sociodemographics are controlled. Those who received no financial support from their family have about seven times the likelihood of being employed compared to those that receive all of their financial support from their family (OR = 7.01, $p < 0.01$).

Table 2. Logistic Regression Predicting Stigma as a Barrier to Employment among ASD Individuals using Data from Interactive Autism Network Research Database, Odds Ratios (OR) and 95% Confidence Intervals (CI) (*N* =222)

	Model 1			Model 2			Model 3			Model 4		
	OR		Std Error	OR		Std Error	OR		Std Error	OR		Std Error
Comorbidity												
Number of mental comorbidities	0.718	**	0.102				0.764	*	0.011	0.762		0.117
Number of physical comorbidities	0.893		0.104				0.846		0.111	0.832		0.117
Social Support												
Living Arrangements												
Live alone: REF												
Live with parents, relatives, or siblings				1.716		0.538	1.417		0.558	1.351		0.59
Live with spouse and/or children				1.547		0.593	1.205		0.611	1.1		0.645
Live with housemates				1.352		0.498	1.264		0.514	1.27		0.55

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Table 2. Logistic Regression Predicting Stigma as a Barrier to Employment among ASD Individuals using Data from Interactive Autism Network Research Database, Odds Ratios (OR) and 95% Confidence Intervals (CI) (*N* =222)

	Model 1			Model 2			Model 3			Model 4		
	OR		Std Error	OR		Std Error	OR		Std Error	OR		Std Error
Financial Support												
All financial support: REF					*							
No support				6.177	**	0.613	5.29	*	0.651	8.014	**	0.741
Less than half				5.543	*	0.652	4.937	*	0.688	5.686	*	0.747
About half				2.098		0.742	2.24		0.772	2.657		0.827
More than half				3.361	†	0.628	3.614	*	0.655	4.855	*	0.71
Sociodemographics												
Race												
Other: REF												
Non-Hispanic White										0.92		0.425
Sex												
Female: REF												
Male										1.214		0.336
Education												
Bachelor's, Master's, Ph.D., or Professional degree: REF												
Less than high school										0.317		0.809
High school, GED, or										0.334	*	0.448
Some college, Associate's or Technical degree										0.378	**	0.359
Age												
50 +: REF												
18-25										2.877	†	0.594
26-29										1.311		0.591
30-39										1.736		0.473
40-49										1.004		0.446

† $p < 0.1$, *$p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

CHAPTER FIVE

CONCLUSION

Discussion

This is the first study examining factors impacting employment among ASD individuals focusing on comorbidity and social support. The increased rate of children diagnosed with ASDs in the United States in the last 20 years means that the adult ASD population is bound to increase substantially. ASDs are lifelong disorders, thus the effect of this increase can be felt in the political, social, and economic arenas. Given the large increases in ASD diagnoses among children (CDC 2013), the stigma applied to those with a mental disability (Goffman 1963), and the fact that those with this type of disability are the least employed among the disabled groups (Shattuck et al. 2012), the issue of employment among these individuals will become increasingly more pressing over time. However, most research has been conducted among children with ASDs. Therefore, in this study I use data from the IAN Research Database to study factors related to employment among the adult ASD population.

Descriptively, the majority of ASD individuals did have comorbidity present; 89.4% had mental comorbidity, and 95.9% had physical comorbidity. This is in line with previous research showing that comorbidity is present in 83% of the ASD population (CDC 2012). These analyses are viewed through the concept of stigma (Goffman 1963; Jones et al. 1984; Crocker, Major, and Steele 1988; and Link and Phelan 2001). Stigma is commonly used to explain why those with disabilities have differences in social outcomes, which include employment opportunities. This research found that those with more mental disability were employed less than those with physical disability. Goffman (1963) states that mental disorders are more associated with a person's identity, and people are stigmatized more because of a mental disorder. Thus, stigma may play a role in the employability of ASD individuals with mental disability or comorbidity.

Bivariate testing showed that physical and mental comorbidity was significant in employment outcomes; however, multivariate analysis showed that only mental comorbidity is associated negatively with employment outcomes, indicating that controlling for mental comorbidities accounts for the negative relationship between physical comorbidities and employment. This suggests that those with one type of comorbidity, either physical or mental, also have the other type of comorbidity. For example, if physical comorbidity is present, mental comorbidity is also present. The findings partially support Hypothesis 1; although physical comorbidity is not significantly related to employment, mental comorbidity was found to be a significant factor in employment. Results suggest that living arrangements were not found to be a significant factor in employment. However, unlike my initial hypothesis (Hypothesis 2), I find that financial social support was <u>negatively</u> associated with employment. Additionally, social support partially mediates the association between mental comorbidity and employment, thus Hypothesis 3 was partially supported. Those with more comorbidity receive more social support and greater levels of social support are associated with decreased likelihood of employment.

Although I expected to find a positive association between social support and employment, the findings of this study indicated a negative association. This could be due to the nature of the social support variables. Living conditions and financial support from family were used to measure social support; however, there are many other ways to measure social support. Social support often is assessed by a person's perception of having someone around who is there when needed, and that cares about the person.

Multivariate analyses show that age, race, and sex were not associated with employment. The results could be different for sex if the data set was representative of the ASD population (four to five times higher rate of men have an ASD than women), since historically men have held more jobs than women, and this is an area where more research is needed. However, education is significantly related to employment such that increasing education is associated with a greater likelihood of employment. Thus, there is partial support for Hypothesis 4. Although age, race, and sex were not significant factors in employment, education is a significant factor in employment. In this highly educated sample, 4.5% of respondents reported less than a high school education; 18.5% reported having a high school degree or equivalent; 33.3% reported having an Associate's or Technical degree; and 43.7% reported having a Bachelor's degree or higher, which is more than the general public. The statistics for the general public aged 25 and over show that in 2010, 31.7% of adults aged 25 and over had a Bachelor's degree or higher (U.S. Department of Education 2011).

Thus, this research shows that having mental comorbidity is a significant factor in employment, as is education. Future research should focus on which mental disorders are more likely to be associated with employment among this population. Comparisons could also be made to the general public and other disabled groups concerning mental comorbidity and employment to see if there is a difference among groups.

This research has implications for policies that concern disabled individuals. According to the ADA (1990), accommodations must be made for the disabled individual, including employment opportunities. This research shows that it is the mental disability, not physical disability, which hinders employment among the ASD population; thus, accommodations should be made for mental disabilities to increase employment among the ASD population. Accommodating mental disabilities in the work environment may be more difficult than accommodating physical disabilities. Although mental disabilities may sometimes be invisible, the employer needs to know about any mental disabilities for their protection and for accommodating the ASD individual in the work environment. The ASD individual may not want to disclose this information, as more stigma may be applied. Stigma is attached more strongly to mental disabilities than physical disabilities (Goffman 1963). There may be confusion over how to accommodate a mental disability such as OCD or ODD. Patience and understanding would be needed, as well as employee training. The individual may also need time to be separated from others as much as possible while at work. Coping strategies may need to be integrated into the work environment, or different lighting or noise reduction. Notifying the individual of upcoming change may also be beneficial. Other strategies may also be needed depending on the mental disability.

Limitations

There were a few limitations to this research. First, this is a cross-sectional survey, precluding causal conclusions. Survey respondents may be different from others, as once self-selects to complete a survey. People were referred to this survey by doctors, ASD websites, and by word of mouth and other venues; this may impact who responds to the survey, as males typically have lower levels of seeking care and those of lower socioeconomic status may not have access to a computer to fill out the survey. In this sample, 64.4% respondents were female, 35.6% were male; this is not representative of the ASD population, as males have a four to five times higher rate of being diagnosed with an ASD over females (CDC 2012). Additionally, compared to the general public, this was a highly education sample, with 43.7% have a Bachelor's degree or higher, compared to 31.7% among the general population (U.S. Department of Education 2011). However, higher education is apparently the norm for employment among this group; the U.S. Department of Labor (2011) states that 59% of employed ASD individuals aged 25 and above have graduated from a four-year institution. The low amount of people in this sample having less than a high school education (4.5%) may have impacted the significance of this measure somewhat, however education was still found to be significantly associated with employment. The majority of this sample was non-Hispanic white (82.9%) and was above the age of 30 (67.1%).

Additionally, since the respondents were adults, parental education or occupation was not a question asked on the survey form. Thus, the ASD adult education level was used as a proxy for socioeconomic status. The social support variables may be different than social support variables of other studies; however, ASD adults may need different social support measures than is normally used in social support research.

Conclusion

Despite the limitations of this study, the results provide an important foundation for understanding the relationship between comorbidity, social support, and employment among the ASD population. Results find that comorbidity is associated negatively with employment. Those with mental comorbidity are employed at a lesser rate than those with physical comorbidity. According to Goffman (1963), people with mental disorders are seen as different and are devalued (Jones et al.1984; Crocker et al. 1998), which makes it harder for these individuals to participate in social life. Link and Phelan (2001) explain how the status loss and discrimination of the stigmatized group leads to a separating of “us” from “them.” Parker and Aggleton (2003) find that this devaluation of a group leads to social inequality. Social inequality does seem to be present among the ASD population, as this is the least employed of all disabled groups (Shattuck et al. 2012). This study also confirms the association between higher education and employment, especially among ASD adults.

Future research should focus on which mental disorders are more likely to be associated with employment among the ASD population. Comparisons among other disabled groups and the general population could also help identify which mental disorders are more likely to be associated with employment. Also, research could be conducted addressing how comorbidity impacts both the employer and the employee in a work environment. Future research should also focus on social support and employment using different social support measures to see if different types of social support impact employment. Also, since education was found to be associated with employment, research should be conducted in this area including researching which type of education is beneficial to gaining employment for ASD individuals. For instance, are most ASD individuals employed in a certain field, such as engineering or computer oriented work? Research should also focus on interviewing employers of ASD and disabled individuals to find what factors are associated with gaining and maintaining employment, and how accommodations can be made for ASD and other disabled individuals. This research has implications for policies concerning disabled individuals. Accommodations need to be made for mental disabilities, especially among the ASD population. Education and training may also need to be incorporated into employment policies to decrease the stigma and misunderstanding accompanying individuals with ASDs.

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APPENDIX A

IAN ADULT WITH ASD QUESTIONNAIRE: SELF REPORT

APPENDIX A – IAN ADULT WITH ASD QUESTIONNAIRE: SELF REPORT

Autism Spectrum Diagnosis

1. What was the FIRST autism spectrum disorder (ASD) diagnosis you ever received from a professional? (If it has not changed, this is the ASD diagnosis you have now.)

- Autism or Autistic disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
- Autism Spectrum Disorder (ASD) (choose only if none of the above apply)
- I never have been diagnosed with an autism spectrum disorder by a professional.

2. Approximately how old (in years) were you when you received this FIRST ASD diagnosis?

3. Please provide the date when you received this FIRST ASD diagnosis. Please indicate the date as accurately as you can. If you do not know the day or month, choose "Don't Know" from the drop down menus for day and month. If you don't know the date at all, click on "I can't answer because...."

4. Who gave you this FIRST ASD diagnosis?

- Pediatrician
- Primary care doctor (other than pediatrician)
- Developmental pediatrician
- Psychiatrist
- Clinical Psychologist
- Neurologist
- Team of health professionals
- Team of professionals in a school system
- Speech and Language Pathologist
- Other

5. Is your CURRENT ASD diagnosis different than your first?

- Yes, the CURRENT diagnosis is different.
- No, the CURRENT diagnosis is the same.

6. What is your CURRENT ASD diagnosis?

- Autism or Autistic disorder
- Asperger's Syndrome
- Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Childhood Disintegrative Disorder (CDD)
- Pervasive Developmental Disorder (PDD) (choose only if none of the above apply)
- Autism Spectrum Disorder (ASD) (choose only if none of the above apply)
- I no longer have an ASD diagnosis (according to a professional).

7. Approximately how old (in years) were you when you received this CURRENT ASD diagnosis?

8. Please provide the date when you received this CURRENT ASD diagnosis. Please indicate the date as accurately as you can. If you do not know the day or month, choose "Don't Know" from the drop-down menus for day and month. If you don't know the date at all, click on "I can't answer because...."

9. Who gave you this CURRENT ASD diagnosis?

- Pediatrician
- Primary care doctor (other than pediatrician)
- Developmental pediatrician
- Psychiatrist
- Clinical Psychologist
- Neurologist
- Team of health professionals
- Team of professionals in a school system
- Speech and Language Pathologist
- Other

Strengths, Abilities, and Special Interests

10. What particular abilities or strengths do you have because you are a person on the autism spectrum? Check all that apply or "none of the above" if none apply.

- An ability to think in unusual, creative ways
- An ability to focus intensely on certain topics
- Honesty
- A sense of justice
- A different way of experiencing the world
- Ability in mathematics, science, or computers
- Ability in art or music
- A very good memory for certain topics
- An ability to focus on small details
- An incredible imagination
- Kindness
- Other
- None of the above

11. Do you have a special interest or topic? (Often individuals with an ASD have an unusually intense area of interest or focus. This is what we mean by "special topic.")

- No
- Yes

12. What type of special interest or topic do you have? Check all that apply if you have more than one. Please use the "I would like to provide additional information with my response" if you would like to tell us more about your special topic.

- Modes of transportation (such as trains, automobiles, aircraft)
- History
- Science (such as astronomy, geology)
- Science fiction or fantasy (in books, films, video games)
- Computers
- Mathematics or numbers
- Animals (such as dogs, fish, horses)
- Movies
- Cartoons or anime
- Maps, calendars, or dates
- Timetables or schedules
- Dinosaurs, monsters, or fictional creatures
- Music
- Art
- Sports
- Sewing or crafts
- Other

13. How does your special topic affect your life? Check all that apply or "none of the above" if none apply.

- My job or career involves my special topic.
- My studies in school or college are (or were) related to my special topic.
- I have relationships based on my special topic. I make friends or join groups focused on the same interest.
- I enjoy activities and hobbies relating to my special topic.
- My special topic sometimes gets in the way of success at work, school, or in relationships.
- The special topic has gotten me in trouble. (For example, it may have led to addictive behavior or breaking the law.)
- Other
- None of the above

Questions About Education, Work, Living Situation, Financial Support, etc.

14. What is the highest level of education you have completed?

- Less than high school
- High school certificate of completion (special education alternative to diploma)
- High school graduate or equivalent (GED)
- Trade or vocational school (certificate or license but no degree)
- Some college but no degree
- Associate's degree in **vocational or technical** program
- Associate's degree in **academic** program
- Bachelor's degree
- Master's degree
- Ph.D. or Professional degree
- Other

15. Are you currently attending school, such as high school, vocational or trade school, or college?

- No
- Yes

16. In what type of housing do you currently live?

- An apartment
- A townhouse, condo, or duplex
- A single-family home (a house not attached to other houses)
- A college or other school dormitory
- An intermediate-care facility, nursing home, or other institutional setting
- Other

17. Do you live with any other people?

- No
- Yes

18. With whom do you live? Check all that apply.

- With a spouse or other life partner
- With my children
- With housemates or friends that I got to choose
- With housemates I didn't get to choose
- With my parents
- With one or more siblings
- With a relative other than parents, siblings, or children (such as a grandparent, aunt, or uncle)
- Paid caregivers
- Other

19. Do you currently have paid employment?

- No
- Yes

20. On average, how many hours per week do you work?

- 1 - 9 hours
- 10 - 19 hours
- 20 - 29 hours
- 30 - 39 hours
- 40 or more hours

21. Would you like to work more hours than you currently are able to get?

- No
- Yes

22. What is your current work situation? Check yes or no for each response.

- Regular employment (with no help or support)
- Supported employment (you may have a job coach or other special help at work)
- Sheltered workshop
- Enclave employment (you may work in a business with a group of other people with special needs, all under supervision of an agency serving people with disabilities)
- Day program that includes work or vocational activities
- Internship or work study program
- Other

23. You have told us you are not working. Please help us understand your situation. Check yes or no for each response.

- Unemployed -- want to work but can't find work
- Have tried to work but faced discrimination or other difficulties with employers because of ASD
- Do not wish to work at present (may be in school, a stay-at-home parent, etc.)
- Not able to work because it would interfere with federal or state benefits (such as disability payments)
- Not able to work because the workplace would be too challenging (because of ASD or other health or mental health issues)
- Other

24. How much, if any, do you rely on your extended family (such as parents and siblings) for financial support?

- My family **does not provide** any financial support for me at all.
- My family provides **less than half** of my financial support. They help me financially sometimes.
- My family provides **about half** of my financial support.
- My family provides **more than half** (but not all) of my financial support.
- My family provides **all** of my financial support.

25. Do you currently receive any federal or state benefits, such as Social Security Disability Insurance (SSDI) or Medicaid?

- Yes
- No
- Not sure

26. What federal or state benefits do you currently receive? Check all that apply or "none" if none apply.

- Social Security Disability Insurance (SSDI)
- Supplemental Security Income (SSI)
- State disability programs that use only state and/or local funds
- Medicaid (for health insurance)
- Medicare
- Medicaid HCBS (Home and Community Based Services) waiver or Developmental Disability waiver
- Employment assistance or job support (sometimes called "Vocational Rehabilitation" or "VR")
- Section 8 Housing
- Transportation services for people with disabilities
- Other
- None

27. Do you suffer from any of the following? Check yes or no for each response.

- Gastrointestinal issues (such as chronic diarrhea, constipation, nausea, vomiting, acid reflux, etc.)
- Allergies
- Sleep issues (such as problems going to sleep or staying asleep)
- Skin conditions (such as psoriasis or eczema)

28. Have you been diagnosed with any of the following conditions by a professional? Check yes or no for each response.

- A seizure disorder or epilepsy
- Asthma
- Diabetes
- Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD)
- Oppositional Defiant Disorder (ODD)
- Obsessive Compulsive Disorder (OCD)
- Anxiety (such as social phobia, generalized anxiety disorder, panic disorder, or some other kind of anxiety)
- Depression (such as major depressive disorder, seasonal affective disorder, postpartum depression, or some other kind of depression)
- Bipolar Disorder
- Schizophrenia
- Other

29. What treatments or interventions are you currently using to help with ASD or other conditions you might have, such as attention deficit hyperactivity disorder (ADHD) or anxiety? Check all that apply or "none" if none apply.

- Medication
- Alternative Medicine (herbs, homeopathic remedies, acupuncture, vitamins, etc.)
- Individual Therapy or Counseling (for example, talk therapy or cognitive behavioral therapy)
- Group Therapy
- Marital or Family Therapy
- Support Group, in person
- Support Group, online
- Spiritual practice (such as prayer or meditation)
- Speaking with a pastor, rabbi, etc.
- Self-help books
- Applied Behavior Analysis (ABA)
- Physical Therapy
- Occupational Therapy
- Speech and Language Therapy
- Social Skills Training or a Social Skills Group
- Life-Skills or Self-Care Training
- Other
- None

What Do We Need to Learn About Adults with ASD?

We are developing a series of surveys for adults with ASD so that people will better understand the challenges faced by adults on the autism spectrum. To help us decide which topics to study first, we are asking you to rate the importance of 15 general topics that are common to daily life.

- Extremely high priority
- High priority
- Medium priority
- Low priority
- Not a priority

30. Understanding and Accepting Adults with ASD (This research will answer questions about how to teach other people, like educators and employers, how adults with ASD experience the world, how they feel, why they behave the way they do, and what they need.)

31. Employment and Adults with ASD (This research will answer questions about whether adults with ASD are succeeding in the workplace, what kind of help they need at work, and whether they have faced discrimination at work.)

32. Education and Adults with ASD (This research will answer questions about whether adults with ASD are succeeding at college or in other educational programs, what kind of help they need, and whether or not they are getting the help they need.)

33. Federal and State Assistance for Adults with ASD (This research will answer questions about whether adults with ASD need and are receiving government help such as supplemental security income [SSI], social security disability insurance [SSDI], or Medicaid.)

34. Financial Issues and Adults with ASD (This research will answer questions about how adults with ASD pay for food, housing, and health care, and if they can afford what they need.)

35. Living Situation and Adults with ASD (This research will answer questions about where adults with ASD are living, who they are living with, and if they are happy with their living situation.)

36. Transportation and Adults with ASD (This research will answer questions about whether adults with ASD have a way to travel to school, work, or other activities, and if problems with transportation are preventing them from living the life they want.)

37. Health Conditions and Adults with ASD (This research will answer questions about how many adults with ASD are coping with medical conditions or mental health issues.)

38. Health Care Access and Adults with ASD (This research will answer questions about how many adults with ASD have health insurance and can get the medical care, dental care, or mental health care they need.)

39. Current Treatments and Adults with ASD (This research will answer questions about what treatments adults with ASD are using to help them with any medical or mental health issues, and what treatments are the most helpful.)

40. Daily Life and Adults with ASD (This research will answer questions about how adults with ASD spend their time, and whether they are satisfied with their lives.)

41. Friendship and Adults with ASD (This research will answer questions about adults with ASD and their social relationships, including whether they are satisfied with their ability to make friends and with the friendships they have.)

42. Romantic Relationships and Adults with ASD (This research will answer questions about adults with ASD and their romantic relationships, including whether they are satisfied with their ability to find a romantic partner, and with the romantic relationships they have.)

43. Sexuality and Sexual Health and Adults with ASD (This research will answer questions about adults with ASDs, their knowledge about sex, their sexual experiences, and their sexual health and safety.)

44. The Criminal Justice System and Adults with ASD (This research will answer questions about what happens when adults with ASD become involved with the criminal justice system whether they have been the victims of a crime or accused of committing a crime.)

Participation in ASD Research

45. Have you ever participated in a RESEARCH STUDY about autism spectrum disorders (prior to this one)?

- No
- Yes

46. Have you participated in a RESEARCH STUDY about autism spectrum disorders after you became an adult (18 years of age and older) prior to this one?

- No
- Yes

47. Have you ever participated in a RESEARCH STUDY about the GENETICS of autism spectrum disorders?

- No
- Yes

48. Have you ever participated in a RESEARCH STUDY about DRUGS/MEDICATIONS for treating autism spectrum disorders?

- No
- Yes

49. What did you think about the length of this questionnaire?

- It was too short and did not ask all of the questions I would have expected.
- It was too long.
- It was just right.

50. In what ways did you hear about IAN prior to deciding to join? Check all that apply.

- Invited by family member already in IAN
- Received a "mass" e-mail
- Television
- Radio
- Print media (including newspapers, magazines, etc.)
- Internet search
- IAN Community website
- Website/online (not IAN Community)
- IAN Research ad or link from other website (not IAN Community)
- Autism fundraising event, such as walk or bike ride
- Conference
- Health care provider
- School
- "Word of mouth" from friend or family
- Participated in IAN as a child, but now adult
- Other

APPENDIX B

IAN BASIC FAMILY INFORMATION - DEMOGRAPHICS

APPENDIX B – IAN BASIC FAMILY INFORMATION - DEMOGRAPHICS

When joining the IAN Research Project, the first step a parent of a child with an Autism Spectrum Disorder (ASD) takes is completing a Consent Form. The Consent Form explains the IAN Research Project in detail. It is also where we gather basic demographic information from families.

The fields a parent is asked to fill in are:

1. **Display Name**

   This is the name a participant wants to appear on the entry screens in IAN Research to designate him or herself. It can be anything - a formal name, nickname, or made-up name. (Note: it is *not* same as the Display Name used in the IAN Community as an anonymous identity for the Discussion Forums.)

2. **First Name**
3. **Middle Name**
4. **Last Name with Suffix**
5. **Gender**
6. **Ethnicity**

   Hispanic or Latino or *Not Hispanic or Latino*

7. **Race**

   Check all that apply: White, Black/African American, Native Hawaiian or Pacific Islander, Asian, American Indian or Alaskan Native, Other, and Unknown.

8. **Street Address**
9. **City**
10. **State**

11. **Zipcode**
12. **Home Phone Number**
13. **When did you begin living at this address?**

    Month and Year
14. **Have you been diagnosed with an Autism Spectrum Disorder?**

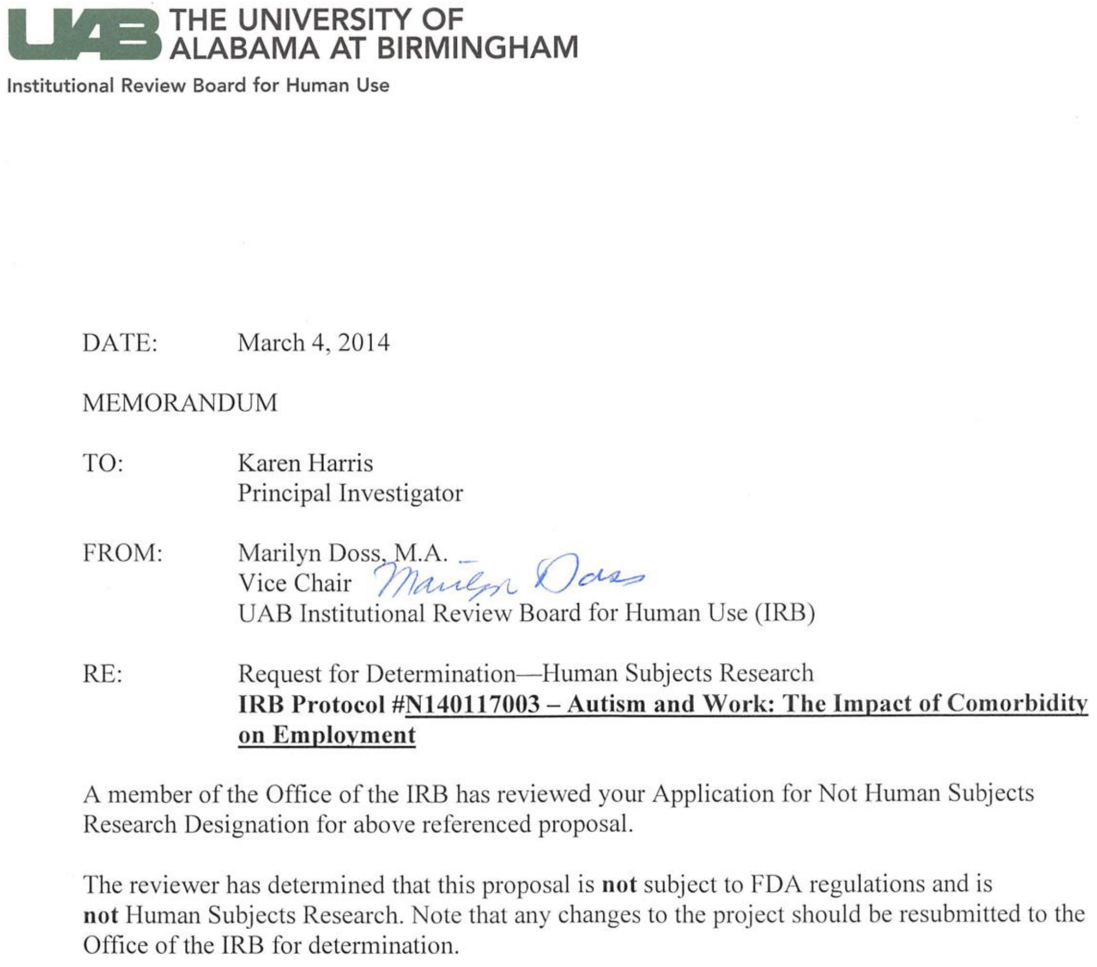
    Yes or No - tells us whether the ***parent*** him or herself has ever been diagnosed with an ASD.
15. **If Yes to ASD question above, please select your *first* ASD diagnosis received from a professional (i.e. physician, psychologist, psychiatrist).**

    Choices are: Autism or Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder (PDD), Autism Spectrum Disorder (ASD).

As a parent adds their children to their Family Profile, they will be asked to fill in a similar Consent Form (with demographic information) for each one.

APPENDIX C

ISTITUTIONAL REVIEW BOARD APPROVAL



THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM
Institutional Review Board for Human Use

DATE: March 4, 2014

MEMORANDUM

TO: Karen Harris
Principal Investigator

FROM: Marilyn Doss, M.A.
Vice Chair Marilyn Doss
UAB Institutional Review Board for Human Use (IRB)

RE: Request for Determination—Human Subjects Research
IRB Protocol #N140117003 – Autism and Work: The Impact of Comorbidity on Employment

A member of the Office of the IRB has reviewed your Application for Not Human Subjects Research Designation for above referenced proposal.

The reviewer has determined that this proposal is **not** subject to FDA regulations and is **not** Human Subjects Research. Note that any changes to the project should be resubmitted to the Office of the IRB for determination.